DOCUMENT RESUME

ED 218 818 EC 142 770

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TITLE Disabled Children and Their Families: The Impact of Public Law 94-142. Revised Final Report--Year I.
INSTITUTION Cambridge Workshop, Inc., Belmont, MA.
SPONS AGENCY Bureau of Education for the Handicapped (DHEW/OE), Washington, D.C.
PUB DATE Feb 80
CONTRACT 300-78-0463
NOTE 152p.; For related document, see EC 142 769.

EDRS PRICE MF01/PC07 Plus Postage.
DESCRIPTORS Case Studies; *Compliance (Legal); *Disabilities; Due Process; Elementary Secondary Education; *Federal Legislation; Individualized Education Programs; Mainstreaming; *Parent Attitudes; Parent Participation; *Parent School Relationship; Student Evaluation
IDENTIFIERS Education for All Handicapped Children Act

ABSTRACT

The report details the case studies of six families with disabled children, ranging in age from 6 to 18 years, as part of a study to investigate the impact of P.L. 94-142 (the Education for All Handicapped Children Act). An introduction points out that a naturalistic case study approach was used to address the parents experiences with P.L. 94-142, as well as the Massachusetts special education law, Chapter 766. Case studies make up the bulk of the document with excerpts given from tape recorded interviews. Among the topics touched on are the mainstreaming of a developmentally disabled child, the parent as advocate, the inefficiency of the process in implementing a disabled boy's individualized education program (IEP), use of the court to obtain proper school services for a neurologically handicapped child, the IEP team meeting, and parent involvement in development of the IEP. Parents' experiences are analyzed in terms of five provisions of the law: protection in evaluation procedures, the IEP, the least restrictive environment, due process, and parental involvement. Noted among findings are that parents are often excluded from the evaluation process, parents report intimidation and poor parent-professional communication during the IEP meeting, parents generally have low confidence in the classroom teacher's competence with regard to mainstreaming, parents likely to exercise due process are emotionally capable of coping with a lengthy battle with the school system and have an adequate understanding of their rights under the law, and parents are rarely valued as partners in the planning of their children's programs. (SB)

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DISABLED CHILDREN AND THEIR FAMILIES:
The Impact of Public Law 94-142

Revised Final Report - Year I

February, 1980

Submitted by

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EC142774

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BEH Project No. 300-78-0463

We wish to express our sincere gratitude to each of the families living with a disabled child who so willingly allowed us to enter their homes, their lives, their hearts. Despite the presence of a tape recorder, they have reached deeply and thoughtfully into their pasts to share with us sometimes painful experiences. They have without exception responded eagerly and candidly to our inquiries. For this, we thank them.

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PREFACE

This is a report about some issues in education and about a small group of people who live these issues every day.

In what follows, we speak often for others, for parents of disabled children who have willingly and candidly shared with us their experiences living with Public Law 94-142. Our aim is to represent them -- their views, their hopes and their concerns -- fairly and accurately.

During the course of our developing relationships with families, we found ourselves unavoidably assuming a variety of continually changing roles. On any given day we might have been observers, interviewers, babysitters, advocates, counselors and/or dinner guests. Our intimacy with the families developed strongly; they would call us for advice and to advise, they asked us on occasion to attend evaluation meetings with them, they came to see us as concerned friends, they opened themselves to us.

During the past ten months we were witness to tears and to tantrums, to quiet happy moments, to despair. For us the experiences were not infrequently difficult, emotional and draining. But for us, unlike the families, these same experiences were also time limited.

To many, the passage of Public Law 94-142 was considered an act of historic proportions. To parents of disabled children, it continues to be a matter of pragmatics, a matter that this report begins to describe.

INTRODUCTION

The Parent Experience

You've got to learn not to let yourself fall apart and not to let your family fall apart. I can imagine how many parents say, "OK, put him in a private school or hospital or something. I don't want to have any more to do with him." I said it myself. I didn't mean it, but I said it. And I hated myself afterwards.

Mrs. K.

We've got a bill for over $200 from the medical center that we have to pay somehow. We'll also be getting a bill for an evaluation that was done at a local college, and we'll have to pay that too. And my attorney's fee will probably come to $5,000. Is it any wonder that I've been going to the doctor for my elevated blood pressure? I blame it all on the superintendent.

Mrs. L.

Last year we had a good program; this year we have a very poor program. So, in the seven years we've been involved with this school system, we've had two good years. We get precious little as far as I'm concerned. Except for aggravation.

Mr. C.

These are typical parents of not quite typical kids. Endless anecdotes. Some about joy and discovery, most about frustration, about strain, about being tired of being tired.

The words and experiences of the parents we came to know over the past ten months are mirrored again and again in critically acclaimed published accounts by parents of disabled children we have never met. Their reflections are clear, telling and particularly appropriate to this preliminary report. Consider, for example, Josh Greenfeld's candid philosophizing on his autistic son:

> Of course it is easy to sentimentalize: how having a Noah gives meaning and definition to one's life. How people without Noahs are constantly searching for humanistic dedications. How a Noah teaches one the values of all the old verities. Bullshit! Without Noah we'd be freer to explore the boundaries of our own lives ... The sonofabitch demands so much -- and gives back so little.
>
> A Child Called Noah
> pp. 152 & 169

Or Helene Brown's often painful ambivalence toward her multiply handicapped daughter:

My luck and my tragedy was Karen. She

> had begun as the pretty baby of my dreams and had turned my life into a nightmare ... I derived pleasure from being with Karen when I wasn't wrestling with the problems she created just by living ... A handicapped child is with you from birth -- forever. He or she is a responsibility that always hovers at the edge of your life.
>
> Yesterday's Child, pp. 36, 145, & 146

Or, lastly, Elizabeth Pieper's attempt to summarize her relationship with her multiply handicapped son:

> Jeff is neither my burden nor my chastisement, although his care requires more than I want to give at times. He is not an angel sent for my personal growth or my future glory; he is not a punishment for my past sins. He is a son.
>
> Sticks and Stones: The Story of Loving A Child, p. 88

These are hard words to read, no doubt harder to have written. But their value in helping to establish a context in which issues relating to P.L. 94-142 can be accurately understood is critical. In this context, apparently isolated, even trivial considerations become integral parts of a family experience with which only a few readers of this report will be able to identify. Listen again:

> While I was waiting for the diagnosis to come in, I was figuring somebody would tell me that my baby would never become anything, that something is terribly wrong with him. That was the longest week of my whole life. At one point I even thought, "You know, if I smother my child and then kill myself, it wouldn't be such a sin." Isn't that terrible? That's the despair.
>
> Mrs. O.

In thinking back, not only over the past ten months to the six case study families and their fifty group meeting counterparts, but also over the past ten years and to the more than 500 parents of retarded and emotionally disturbed children we have come to know well, the image that comes closest to capturing the spirit and substance of the parent experience is that of individuals always grappling, often fighting, almost never complacent. We think of parents who seem to have to strategize more than most, who never have quite enough time, certainly for themselves, and who almost always display a sharp, wry, understated wit. We think, too, of "grace under pressure" and of frequent pressures. These are hard working parents, cautious parents, rarely certain parents. They worry a lot. And they constantly grapple with people who ought to provide and don't, with ideas that ought to make sense and don't, with responsibilities that ought to be met and usually aren't. These are parents with extra expenses, not all of them in dollars and cents.

There is no research to demonstrate whether or not these parents differ significantly from their friends

who happen not to have given birth to a disabled child. There is only unrelenting anecdotal evidence attesting to qualitatively different family dynamics, to what must be a remarkably similar collection of internal dialogues shared only among families with disabled children.

We remember for example, the twelve year old sister of a ten year old retarded brother defining retardation as, "My mother breaking into tears for no real reason." And we recall Joseph Heller's fictional father making this poignant judgment about his retarded child in Something Happened: "He has let us down."

Finally, we remember only months ago one mother offering her definition of the parent experience:

> When you have a handicapped child, your whole life revolves around her. You don't know how grueling a task this is.
>
> Mrs. L.

PROCEDURES

A. Sample

The parents of disabled children whose views and experiences are expressed in these pages can readily be found in any community. They are vocal, involved, opinionated, and they are concerned about the education of their children. They are grappling with their rights and their responsibilities under P.L. 94-142.

We have met sixty parents in and around the Boston area in individual and small group meetings over a period of seven months. The length of these meetings ranged from one to three hours and took place in the living rooms or kitchens of the parents' homes.

Parents were located by contacting local Parent Advisory Committees (PAC), special education directors, and, in some cases, friends of friends. The intent of these meetings was to record parents sharing their experiences with P.L. 94-142, as well as with Massachusetts' special education law, Chapter 766.[1]

[1]Since Chapter 766 presently complies with all of the mandates in P.L. 94-142, and since the former is much more familiar to parents, the two laws will be used synonymously throughout this report unless it is clear that a parent is referring specifically to the state law.

Without exception, parents offered information eagerly, candidly, seemingly grateful that someone cared to listen.

Although the majority of parents we met were mothers, twelve fathers also attended evening meetings, and proved to be as vocal and as lively in discussions as their wives.

While we did not ask parents to divulge annual income figures, it is fair to assume that the largest proportion of parents were in the middle income bracket. These parents had children ranging in age from three to twenty two, covering the range of disabling conditions.

During the final five months of the first year, we developed more intimate relationships with six families who agreed to participate in an extensive case study examination of the impact of P.L. 94-142. These six families range in SES level from low-income to upper middle class; four live in urban areas, two are from upper middle class suburbs; three of the families have disabled children who are six years old and in self-contained special education classrooms in the public schools. A fourth family has a child who is presently eight years old, attends a parochial school, and was diagnosed this year as having a mild learning disability. The remaining two families have developmentally delayed teenagers. Mrs. O'Connell's fifteen year old son is mainstreamed into a regular public junior high school and Mrs. Rossi's eighteen year old Down

Syndrome daughter (the only girl among the case study families) is in a substantially separate classroom within the public schools.[1]

This is a uniquely positioned group of individuals insofar as P.L. 94-142 is concerned. To them, such terms as "disabled," "special needs," and all the rest hardly refer to abstract problems. Their stake in how P.L. 94-142 progresses could not be more direct, more personal or more everpresent. At the same time, their experiences with professional promises, with disappointments in the service delivery system, cause them to be wary, often distrustful, sometimes adversarial.

B. Approach.

Ours was a naturalistic case study approach, a molecular view of the effects of P.L. 94-142 on the lives of six families. Generally, our approach was structured in the form of interviews and observations; at times it was allowed to follow its own lead naturally. Always, it was continuous. The ups and downs of any particular day or event would never unduly influence the findings of our long-term investigation.

Most of the time with each of these families was spent engaged in tape recorded interviews, as this proved to be the most efficient and, for the families,

[1]The names of the families and the communities in which they live have been changed to preserve confidentiality.

comfortable means of gathering appropriate information. Each family was interviewed for approximately twelve hours over the course of the study with no interview lasting more than two hours. Frequent telephone conversations, inititated by some of the mothers during periods when "something was up" and the child's educational program was being affected, augmented the interview materials. In addition we attended IEP meetings with parents, and made informal observations of the child and other family members in the home.

Were the six sets of parents included in the study representative of the general parent population? In an empircal sense, of course, they could not have been, and from the outset, concern for the external validity of our findings played a very small role in sample selection. However, in a naturalistic sense, they of course must have been; each of them after all, is a parent of a disabled child.

The long-term values of our findings, therefore, rests on the interpersonal foundations we were able to develop throughout the first year.

C. Central Questions

> You've got to be careful not to sell your kid short. If you've got a handicapped kid, you do have to be more assertive, and it is never ending. You've got to bite the bullet: There is no resting place. There are small areas of refreshment ... but you've got to be realistic ... At some point you realize it's a lifetime chore.
>
> Mrs. O.

Characteristically, from the time a disabled child is born, his or her parents find themselves following a well travelled itinerary that can include numerous stops at diagnostic clinics, hospitals, referral agencies and varieties of public and private service providers. Their itinerary is a long one, typically involving much circling and rerouting; the maps that guide the journey are infamous among parents for their lack of clarity and currency. And, not infrequently, confusion over the foreign language of professionalism contributes to a less than satisfying trip.

Public Law 94-142, in a very concrete way, impacts upon the quality and quantity of these parent travels (travails?). It maps a clear route along a straight path to a logical destination. At least, in the minds of most parents, this is one effect the legislation was supposed to contain; it would simplify their searching. It would describe a set of procedures, appropri-

ately involving parents, that would lead straightforwardly toward ascertaining and then programmatically responding to the child's strengths and weaknesses. It would not, in all cases, obviate the itinerary, but it would make for a more streamlined, more sensible and more satisfying journey.

How well has Public Law 94-142 measured up to its advance billing? How has it performed for parents? With parents? How has it accomodated in particular those parents who accepted its invitation to become actively involved in their children's educational programming? And what have been the effects upon these parents and their families of assuming their new responsibilities under the law? These are the central questions which the present study begins to address.

CASE 1: ROBBIE

CASE 1: ROBBIE

INTRODUCTION

The fifteen-year old O'Connell twins are tall, attractive freckled teenagers whose thick flaming red hair proudly annouces their Irish heritage.

Sheila is friendly, talkative and energetic. She bubbles with enthusiasm over seeing The Clancey Brothers in concert, learning to play the tin whistle, or teasing a favorite English teacher--one of the few men in her all girls' parochial high school. She discusses, with similar intensity, her favorite books, the difference in literary tastes between her father and herself, and her life as a teenager in an affluent suburb. Her energy remains high when she relates favorite anecdotes of times she and her brother Robbie have enjoyed together.

Robbie is more reticent than Sheila. He extends his hand to greet a visitor, but typically shifts his eyes downward or looks slightly away. Although he doesn't often initiate a conversation, he soaks in what is going on around him and is likely to throw in a wry editorial comment on occasion.

Robbie lives with a major complicating factor--he was diagnosed at six months as having brain damage. His delayed development became obvious to his parents, Mary and Robert, early on as Sheila proceeded to reach her developmental milestones "right on schedule."

Robert and Mary have supper together each night after the children have finished eating. Dinner time is their opportunity to catch up on the events in each other's lives. During more suppers than could be counted over the past fifteen years, the subject of Robbie was to dominate that time together; late night dinners becomes a forum in which strategies were planned, support was shared, and emotions were expressed.

As a child with special needs, Robbie has demanded more time and more energy from his parents throughout the years than has Shelia. Although Mary is not certain about the hidden impact that having retarded twin may have had on Sheila, there have been some recent indications of its complexity, as the following incident reveals.

The strongest common interest between Robbie and Sheila is Irish folk music, particularly the Clancey Brothers. In fact, listening to their music is such a pleasure to Robbie, that he will work hard all day in school to earn the opportunity to hear their records at home in the afternoon. Not long ago, however. Sheila expressed anger that Robbie is allowed to monopolize her phonograph each day to earn his reward.

Mary, knowing how unlike Sheila it is to become angry over sharing with her brother, pursued the matter further and heard Sheila summarize the source her frustration: "Robbie gets all the attention." Painfully aware of the truth behind her daughter's anger, Mary responded as simply and as candidly as she could: "It's been that way for 15 years; your father and I were hoping you wouldn't notice."

The following pages unfold the events leading to Robbie's becomming the first developmentally disabled child in his community to be mainstreamed throughout most of his educational career. The report will be conveyed largely through Mary's eyes--the fifty year old self-taught advocate for the rights of retarded citizens.

1. THE EARLY YEARS

Mary O'Connell was born in Pennslylvania, into an Irish coal miner's family in the midst of the depression. She looks back on her early years at home with pride and respect for her parents and the values they instilled.

> My father had brothers much older than he. Everyone in his family belonged to the United Mine Workers when it was very difficult to be affiliated with that group. When my father grew up, there was no question but that you lived in a company house--they owned it and you payed them rent. They also forced people to buy at the company store where they set their own rates. I remember when I was a little girl, my father used to tell me about his mother who refused to buy in those stores; I was very proud of his mother because she wouldn't do that.
>
> My father's brothers and my father himself always spoke disparagingly of anyone who didn't belong to the union, but who shared in the benefits, if you know what I mean. The other thing which would incense my father was when someone would use the group for his own purposes or his own self-advancement, or something that was not solely for the organization.
>
> The image I grew up with was that you speak out, you speak out for everybody. You never just take yours and leave. Discussions at home typically involved politics, the working class, and union-related topics. I think my father was always interested in politics and the law, and that spilled over to both my sister and me.

It was the local parochial school that provided Mary's education through high school. When she turned eighteen, she went away with a scholarship to a Catholic girl's college; the experience was short-lived. "I didn't like that school at all. It was terrible--sort of like Attica,"

she laughs, remembering all the rules and restrictions. She returned home after one semester, and attended a business college ("...where I learned how to type") and went on to work for a savings and loan company.

When she turned twenty-one, Mary left home to join some friends who were working in Washington D.C. Before long, she was hired as the secretary to the Director of the Political Action Committee for the Congress of Industrial Organizations (CIO). She fit in well working in the labor movement with the coal miners and others interested in labor unions. Mary fondly remembers sharing a sense of family throughout the twelve years she worked with the AFL-CIO.

Robert O'Connell was working for the Census Bureau in Washington when Mary met him. When they decided to get married, Mary was thirty and Robert was thirty-two.

> Nothing bad had ever happened to either one of us in our whole lives; we had never been ill. Living during the depression was difficult, but everyone went through that together. Mostly I was very lighthearted and gay, which is something you can only be at a certain time in your life. If you wait, you can't do it--you're too old.
>
> But do you know when the lightheartedness began to diminish? With Robbie. Not when he was born, and not with his disability, but when we started to look for services. It really did, without a word of a lie, take the flavor out of life.

2. THE TWINS ARE BORN

The twins were born after four years of marriage, by which time Robert's job had taken the family to Massachusetts. Robert and Mary's surprise and elation at having twins was, however, undercut by some complications the newborns were having: Sheila was obviously premature, and Robbie had to be resuscitated.

> The pediatrician came to me in the hospital when my head was clear and said, 'When you see the boy, don't be alarmed. His jaw is pushed in and his head is misshapen, but it will all fill out.' And then they brought Robbie to me. The first thing I did was to put the bottle in his mouth, and he didn't suck! I immediately asked the nurse to tell me what to do, suspecting nothing was wrong with my baby, but rather with the bottle!
>
> I liked children and was excited about having my own. But I knew nothing, about children or child development. I used to go down to the library to discover anything I could that would help me understand why one baby would be slower than the other. In retrospect, even in the earliest days there were signs of delayed development, but when the pediatrician said to me 'I think he will be all right' I thought he meant that Robbie was going to live. I never suspected he might be talking about brain injury.

With Sheila as a day to day comparison, however, Mary was forced to realize that Robbie was slow in developing.

> One day Robbie almost choked while he was eating, and I realized then that even his swallowing was coming slowly.

Mary tried to ignore the reactions of her relatives and friends to the differences in Robbie, but that didn't help ease the pain or worry they inadvertently exacerbated:

> I remember we went to a christening for the infant of a relative, and people started to look oddly at Robbie because he drooled a lot. He must have been five months old at the time. I felt very uneasy. In fact I felt sick. These were kind people in the family, and I just got a sense from them that they were not happy with my baby's development.
>
> Just about a month later, Robbie seemed to blossom and in my mind anyway, he seemed to catch up. We went to the pediatrician for a regular check-up and I said to him, 'You're going to think I'm crazy, but I was so worried about this little boy. I had begun to think something was wrong with him.'

With the uneasy subject finally broached, the doctor then mentioned his concern that Robbie's head seemed to be growing at an abnormal rate. While Mary sat in his office, speechless, the pediatrician called a neurologist to arrange for an evaluation to be done the following week.

3. THE DIAGNOSIS

> I spent the longest week of my whole life waiting for the appointment. I was expecting somebody to tell me that this baby would never become anything; that something was terribly wrong with him. At one point I even thought, 'You know, if I smother Robbie and kill myself, it wouldn't be a sin.' Isn't that terrible? I mean I wouldn't do it, but that's the despair.

After examining Robbie, the neurologist suspected a hydrocephalic condition and recommended that he go to the hospital for a three day evaluation. Mary was so nervous she made her husband answer the phone when the neurologist called with his final report.

> The news was that Robbie was not hydrocephalic, but that there was brain injury. The neurologist was very certain about the diagnosis. 'But,' he added, 'in a few years, you won't be. You will start to get apprehensive about it again. The only thing I ask of you is that you do not go from doctor to doctor, because there are many in the field who will take your money, and give you nothing. When the time comes, you call me and I'll give you the names of two good poeple to see at another hospital.'

Mary remembers saying to him, "Well, we don't know if he's mentally retarded," and he said, "no we don't." She replied firmly, "Then I don't want people to treat him as if he were mentally retarded, only to find out that he isn't. Because then it would be too late."

"That was my big concern," Mary recalls, "not that he was or wasn't retarded, but that he might be shortchanged."

Many factors following the discussion with the neurologist combined to make the subsequent years increasingly difficult for Mary and Robert. Not only did they have to face each day the growing difference in development between Sheila and Robbie, but they were also left to wonder exactly what it was they should be expecting from him. And, eventually, his behavior became more demanding, more obviously inappropriate for a child his age.

> When Robbie was almost five, the neurologist told us that we should think about sending him to a nursery school, and I said, 'Where do we find one? Is there a private one nearby?' He said, 'Oh, don't spend your money now. The Department of Mental Health runs a clinical nursery program for retarded children in your town.' I said, 'But nobody said he's retarded,' and he looked at me shocked, and said, 'Well, he is.'
>
> I knew it too, but I still would have opted not to think he was retarded. I wanted to somehow avoid that label...That neurologist was a very good man. He followed Robbie all those years for $10.00 a visit. But at this point, he sort of discharged us, and sent us to the educators.

4. NURSERY SCHOOL

When Robbie was four, Mary discovered a home stimulation program offered by the Department of Mental Health. With persistence, she succeeded in securing a teacher to come into the home twice a week to work with Robbie. In no time, these visits from Miss Turner became high points in Mary's week. It was from Miss Turner that she was to learn one of her early, important lessons in advocacy.

> Miss Turner agreed with the neurologist that Robbie was ready to attend a clinical nursery school. The Department of Mental Health had a program in our town, so she went with me to enroll Robbie in it. In her own lady-like way, she never went away. She was so delicate, and polite and friendly, but she never went away! That, I learned, is the whole key to advocacy. You stay with it because everybody counts on you getting tired and going away. Miss Turner wanted Robbie in that program, so she pressed the issue with DMH and she pressed the issue with the teacher, until eventually Robbie was to go two afternoons a week.

Mary was nervous about sending Robbie to nursery school. She felt he was still too small and too young; so much needed to be done for him. But she was also convinced that ultimately they would both benefit from his attending. She anxiously anticipated the first day and was sorely disappointed by its outcome.

Mary's first meeting with Miss Finnegan, the classroom teacher, was business-like and unsettling. There was another mother present, and both she and Mary were surprised at the number of rules Miss Finnegan announced for the two hour program. Eventually, Miss Finnegan turned to tell the other mother, "If Robbie doesn't make it, you have all the information and your daughter will be ready to come; she is first on the waiting list."

Mary was shocked to think there was any doubt that Robbie would "make it." She turned to take a look at the other kids in the class. They were cute, most had Down Syndrome, and all were well behaved. Mary was painfully aware of the fact that Robbie cried often, and was known to disturb other children. She looked at the aging Miss Finnegan and prayed for the best.

> One evening, soon after Robbie had started, Miss Finnegan called me to say that she thought Robbie wasn't quite ready for the program and that he should perhaps come back next year. This was the kind of thing I was to hear all his life: 'Robbie isn't ready.' And if I had paid attention to it, I'm sure Robbie would still be sitting home waiting to be ready for whatever the big event in his life was to be!
>
> So, then, back into the depths of depression. I said to Robert, it's going to be a long road to Harvard. He's already flunked pre-nursery school for retarded children! They told me to take our blanket and leave!

That same night, Miss Turner called and heard the whole story from Mary, although Mary suspected that she had already been well informed of the day's events. When Miss Turner supportively responded with a determined "Don't worry," Mary hardly felt relieved. It was the following day, when she received a phone call from Miss Finnegan stating that she had reconsidered and that Mary should bring Robbie back to the nursery school, that she found herself impressed with and inspired by Miss Turner's skills as an advocate.

> She would never promise something, or complain and say, "Isn't that terrible?!" She just said, "Don't worry," and then she <u>did</u> something. She <u>acted</u>. She was truly a wonderful person who had been doing this all her life. Robbie was back in his nursery school.

Mary was learning the advocate's strategy, and quickly had her first opportunity to apply it to problems Robbie and his classmates were having with transportation. When Robbie first started nursery school, he was picked up by a cab at 11:30 a.m., even though the school was no more than two miles away and the program didn't start until 1:00 p.m. Robbie was forced to ride around town doing nothing for 1½ hours. Mary was upset but figured there were no options.

When Robbie started school full time the following year, he was picked up by cab at 10:00 a.m. for a program that was supposed to start at 9:00. This absurdity upset Mary enough to start her to make inquiries. The cab company explained to her that with the snow plows on the road and with the heavy traffic in the morning, traveling earlier was too difficult. Mary soon learned, however, that excuse was only a part of it; she discovered that the cab driver's schedule in the morning required him to take a student to a program outside their community.

> I knew there had to be a simple solution to this foolishness. I called the Department of Special Education and I asked who pays for the transportation service. They told me they did, which was true at the time, so I asked how they gave out the contract. No one could tell me that, nor would they give me that information at the town hall. So, I called the owner of the cab company, and I said, 'Obviously, you need another cab.' The cab company just muttered. Then I threatened to ask the town to look for another contract. The next day, there was another cab on the road, and Robbie got to school on time.

5. PUBLIC SCHOOL

As Robbie approached age seven, he had outgrown the program in size and skills. Mary was thrilled to hear that the Southtown schools maintained special education classes, and that Robbie would be able to attend a regular public school. She registered Robbie to start in the fall, without even thinking to first visit the program herself.

> I just assumed there was a loving, caring special education class up there. Now I ask myself, why would I think that? Robbie would go off every day and come home looking very disheveled, but I really didn't think much about it. Then one day when I was up at the thrift shop run by the Southtown Association for Retarded Citizens, I was introduced to a woman who immediately said, 'You're Robbie's mother. He gives them more trouble in school than my son.' And I said, 'Oh, no, he's just a little seven year old. That couldn't be. And besides, he just started.' She insisted, saying, 'No, he's up there always screaming.' and when I looked a little closer at Robbie when he came home, I saw that he really was tear-stained. I thought, what is happening to him?

A few days later, Mary and Robert attended a school "open house." They saw that the teacher's arm was scratched and they heard her blame all of it on Robbie's tantrums.

> Robert and I said, almost in unison, 'And what do you do?' We didn't mean it accusingly, but we wondered, what does she do at these times? Well, she took great offense at that. I often think that if we had not said that, maybe we could have changed the direction of the whole thing. But she took it as an affront to her professionalism, and it became very difficult to communicate.
>
> Then I started thinking. I realized there had been no transition period for him. How does he manage

in the cafeteria? He's never been in one before. I should have known with all the noise and confusion what Robbie would do. I should have known you just couldn't plunk him from the nursery school and put him in this new setting with no support. I should have known. Why I let them do that, I don't know. I guess I just assumed they would know how to handle him and his behavior problems.

Soon, the principal started calling Mary regularly to complain about Robbie.

> The first time he called, he said, 'This boy of yours is violent. He should be in an institution. He's completely out of control, he's abusing the teacher, and I won't have it!' I immediately suggested coming to the school to meet with the principal and the teacher, but he wouldn't agree to that. He just wanted Robbie out of his school.

Mary was more than a little disturbed by this phone call. She wondered whether Robbie should be given tranquilizers and consulted with her pediatrician about such a recommendation. Initially, the doctor counseled against it, recommending instead that she and Robert encourage the teachers to be more understanding and allow Robbie the time to adjust to a new situation. When January came and the complaints persisted, all agreed to try Robbie on some behavior control drugs. Eventually, Robbie was taking Ritalin regularly.

> Ritalin just zonked him out. I used to give it to him and just say 'Goodbye Robbie' and watch as his little body got in the cab for school. Why I agreed to that drug, I don't know. But I didn't have anything else. In the meantime, the principal's telephone calls didn't let up.
>
> I got a notebook, and kept it on my refrigerator close to the telephone, where I could easily write down everything he said. That was a little tactic I learned from watching the school folks, themselves. One day in a meeting, the assistant superintendant

> of schools had casually said to a teacher, 'Start making your anecdotal notes.' And I thought, of course, that's what I must do, too. Because sooner or later we're going to have some conflict or other and I'll have nothing but a vague story, and they'll have careful notes. Robert thought I was absolutely paranoid, but I felt I had to start keeping my own records.
>
> Eventually March came. I've since learned that March is when they set up the classroom schedules for the next year: who gets what kid, that sort of thing. Of course, they tell parents nothing. But I became suspicious when, for the first time, they started sending formal notes home to us, complaining of Robbie's behavior.

Mary and Robert attended another meeting with the school staff to hear Robbie be yet again, denounced as a student. "I asked if he was still 'attacking' the teacher since he had begun taking Ritalin. They said, 'No, he doesn't do those things now, but he's not participating. He's not getting anything out of the class!'"

Mary was suspicious that this was the school staff's "subtle" way of letting her know that Robbie wasn't going to be allowed back; her experience told her that they were quite practiced at this approach. She asked if she could come and observe the class and got a flat "No" in response: "Your presence will upset the other children too much."

At the time, Robert had a political contact who arranged a meeting for him with the Director of the State DMH. Robert wanted advice on how he and Mary could get the Southtown Public Schools to keep Robbie in their program. The Director explained that they couldn't, that the school was totally autonomous, but he offered to get Robbie enrolled in a different program. Mary explains their reaction to the surprising news with determined conviction.

We thought about the Director's offer for a while, but something instinctive told us not to accept it. That's not the way to go, we thought. The saying in those days was 'Hell, no, we won't go!' Robert and I decided we would make the public schools educate our son.

One day, when the school bus came by, I just got on it with Robbie. I wanted to see for myself what was going on. I first discovered that his ride to school took almost an hour; it went all over the city. No wonder he was upset when he finally got to school!

When we got there, we went in the back way. There was no one there to meet the kids; they just popped in on their own. I watched Robbie go in and sit down and take some books from the book shelf. I took him by the hand and said, 'Sit here with the group.' The teachers ignored him the whole time, but of course, I was there, and they obviously weren't too pleased with that. Every time they went to do something with the group, I just tugged Robbie by the hand and he'd do it too. In fact, I sensed that he wanted to do it. Of course both teachers were chilly to me; you can imagine. I asked them, 'Do you ever encourage him, as I'm doing?' They answered simply, 'He'll do nothing.'

Then it was time for recess. The teachers opened the door to the corridor, and suddenly every kid in the school was running and screaming down the hall. Robbie and his classmates were expected to step out into that chaos. Robbie just couldn't do it; that was asking the impossible. I waited for things to settle down, then I walked out with him, and I said to one of his teachers, 'That's one of his problems right there. Apparently he's fine until recess, but dealing with loud noise and chaos has always been a problem for him.' She didn't answer. Following a brief disappearance, she came over to me and said coldly, 'It has been decided that you must leave.'

'Who decided that?' I asked. She answered, 'I'm not at liberty to say. But you must leave now.' Of course I knew it had been the principal's decision, but I continued my discussion with the teacher anyway. 'But I'm just beginning to observe his day.'

She replied, 'I can't speak to that; you should leave.' I said, 'O.K., you tell your decider that I will be back, and next time I'm going to stay. Whoever decides these things better get used to that right now.' Then I took Robbie, and we walked out the door.

6. EXCLUSION

During the spring months Mary tried to determine the status of Robbie's education program for the following year. Soon it was the last day of school and her queries remained unanswered.

Summer passed, and it was September that brought the news Mary and Robert had most feared. To this day she cannot recount it without tearful emotion. On the first day of school, Mary saw the bus go by carrying a child from Robbie's class. The next day she flagged down the bus and put Robbie aboard. The Guidance Department promptly called to relay the news that they had no educational plans for her son.

Mary struggled to regain control of her voice.

> In the meantime, the Pennsylvania decision had come down, and was being widely publicized. There was a movement going on in education, and we were encouraged by it. It was going to be harder for schools to exclude our kids. This message was becoming louder and clearer.

Mary thought back over the resources she might have. The previous year she had telephoned the State Department of Special Education at a point when she was particularly concerned about the threatening phone calls from the principal. "I got the number from the Yellow Pages; that's how much I knew!" Mary spoke briefly to a man who told her outright that the principal was talking "the language of exclusion," and explained to her that if her child was to be suspended from school for more than five days,

she had the right, as a parent, to appeal formally to the School Committee. Her conversation was cut short by this staff member's supervisor who had apparently overheard his end of the conversation and put a stop to it immediately. Mary, however, appreciated, remembered, and made the most of the information she received.

On the fifth day of Robbie's exclusion, Mary wrote out the whole history of his school experience in a letter to the Superintendent with copies to the School Committee. "I was so glad to have kept all those wonderful notes!" she remembers. Robert added a tough conclusion to the letter, asking for an immediate written response. Mary and Robert heard right away from the Superintendent with the news that the Guidance Department would work out a program for Robbie. By this time, however, Mary was convinced that the teachers' ineffectiveness, the principal's complaints, and the official exclusion meant that Robbie could never be comfortable in the first school. She worked out a compromise with the Guidance Department: Robbie would attend the grammar school located a block away from his house for two and a half hours each day. His program would be strictly academic; he would see a tutor on a one to one basis throughout the year.

It was soon after Robbie began in his new program that Miss Bancroft, the third grade teacher, met him. When she saw that he was spending each day all by himself with a tutor, she took an immediate interest in him, and she invited him into her classroom. She later told Mary: "If he hadn't sat down, I probably would have lost any interest in him. But, he sat down and I saw immediately

that he wanted to be part of the group." Miss Bancroft invited Robbie to join her class permanently, once his morning tutorials were completed.

Mary's appreciation for this woman's sensitivity and talents is reflected in the glint in her eyes.

> I had two marvelous years. It was almost as if I were in school with him; I felt that relaxed. The anecdotes were endless --the kids in his class would tell me everything he did. But with thirty six kids and only one aide, Miss Bancroft could really manage his behavior--and teach him a few skills while she was at it! The two years Robbie spent in that classroom were truly gifts.

7. CHANGES

Because the new grammar school was so close to their home, Mary used to walk back and forth with Robbie each day. She recalls with pride the kind of slow but dramatic changes that occurred during Robbie's two years in Miss Bancroft's class.

> Sometimes I would go up to the school early and hide behind a tree to watch the kids in the playground during recess. There would be a hundred children outside and no one would see me but Robbie. It was as if he had a radar. But it was painful to watch him on the playground with all those regular kids.
>
> Then one day, I went up to get him after school, and I couldn't find him! He was actually lost in the crowd, looking just like the other kids! His posture, the way he walked, everything.

Toward the end of his second year in the third grade, however, both Mary and Miss Bancroft recognized something awkward about Robbie among children two years his junior; he was rapidly outgrowing his classmates. His self perception began to take priority in their educational plans for him as they both observed him more closely.

This need for a change occurred in 1974, the first year that Massachusetts' new state education law was being implemented. Chapter 766 allowed Mary and Robert to participate with a team of professionals in developing an individual education plan for Robbie. Because he had completed two successful years in a regular classroom program, everyone agreed that Robbie's new program should resemble, as closely as possible, the one he was leaving.

The results of the O'Connells first IEP meeting were that Robbie would continue to see his tutor for two and a half hours each day on a one to one basis to work on readiness skills in academics. He would also be integrated alternately with the three fourth grade classrooms for social studies, science, physical education and art. Everyone on the team seemed confident that this educational plan would meet Robbie's needs.

The new school year began with the news that Robbie's tutor had left to have a baby, and that she would be replaced by a woman, who, upon their initial meeting, left Mary with the impression that she was absolutely terrified with the idea of teaching Robbie. Mary fully expected this woman would "relax" once she had the opportunity to work with Robbie awhile, but when she started receiving phone calls from her almost immediately, complaining about all the trouble she was having with him, Mary and Robert once again experienced deep concern.

Miss Bancroft crystallized their fears when Mary ran into her at the supermarket soon afterwards. Robbie's former teacher told Mary that she was concerned because she didn't think Robbie's educational plan was being properly implemented. She was afraid he was being shoved around. She informed Mary that Robbie's new tutor had never even taught school before. Only later did Mary learn that this same woman was the sister of a counselor from the Special Education Department in Southtown.

> At the same time, it wasn't surprising that I noticed something new and very odd about Robbie: he was becoming terrified. He mentioned one of the fourth grade teachers by

name and he said to me, 'She says Robbie get out of here.' Now, she never said that to him outright, but that's what he heard from the way she was behaving toward him.

Mary candidly admits that she did little about these initial problems.

I let it drift for a number of reasons. You get tired; you get scared. Nobody was complaining to me, so I just let it be. Isn't that terrible? But that's the truth, or at least it was then. Now I realize of course, that that's exactly when you should intervene, when no one's complaining to you. That's when you have the time to be up at the school, looking at the program, following through...but I was very negligent that year.

Mary's lack of involvement didn't last the whole year. One day, she spontaneously visited the classroom where Robbie was supposed to be.

All the kids were watching a movie, I thought that was great; that's the sort of thing he's in the regular classroom for. Except, he wasn't in the room.

She found him down the hall in a regular classroom which wasn't in his educational plan. He was sitting in a corner of the room with two emotionally disturbed boys, "just sitting there at a table doing nothing," while the rest of the room was busily engaged. Mary immediately called the Guidance Department counselor to find out what was going on.

This woman whisked me aside and said, 'Oh,

those fourth grade teachers! They haven't wanted him. It's been terrible. They're not good to other children either.' I said, 'Well, I think we should speak with the liaison who is coordinating Robbie's program.' She agreed, adding, 'That's who is really responsible for this!' We reviewed Robbie's IEP and who do we find is the liaison? The Guidance Department! Mary laughs heartily as she recalls the joke on the school. 'But don't forget' she adds 'this was still early in the development of Chapter 766, and nobody was really thinking of the IEP as a meaningful document yet.'

Mary decided that the room-switching incident she had unexpectedly witnessed should be dealt with in some way. She wanted to prevent it from ever happening again. She contacted the Southtown Department of Special Education and recounted the incident to the Special Education counselor. "It has never happened before and it will never happen again," the counselor explained. "It's just an isolated incident."

When Mary pointed out how odd it was that she should have happened upon a once-in-a-lifetime-event, the retort became bitter. "I think, Mrs. O'Connell, that you should be grateful that Robbie has such a wonderful tutor!" Mary decided to hold back nothing: "I think your sister should be grateful that she has Robbie and found a job!"

8. MAKING A NEW YEAR WORK

Mary and Robert were ready for a frank answer to the central question they faced--who really had responsibility for Robbie's educational plan? Prior to their next IEP session, they called together the principal of Robbie's school, the Guidance Department counselor, and the Special Education Department counselor whose sister was Robbie's tutor.

> When we got to the meeting in the principal's office, it was obvious to me that the whole scene was rehearsed. The Guidance Department woman kind of threw herself around and started to cry and scream at me and Robert that there was a hidden agenda, that we were coming to get her, that Miss Bancroft, who had been so good to Robbie, had formed an attachment and wouldn't let go of him. That was why we didn't like the fourth grade teacher. Now, don't forget, this is the woman who told me how bad the fourth grade teachers were--all three of them. She claimed that she had been so good to Robbie, and this was the thanks she got!
>
> Then the woman from the Special Education Department said that she, too, knew that Robert and I had a hidden agenda: that I particularly didn't like the Director of Special Education. She went on and on, and stated finally that it was a shame that the Guidance Department woman had been treated so abusively by parents like us. Throughout both tirades, Robert and I simply sat and listened.
>
> When they were finished, I said, 'I think

we'd better leave now. We'll come back when you can control yourselves, and then we can have a discussion.' Immediately, the hostility ceased, the carrying on stopped, and we got down to business.

Robert and I were walking home after the meeting, and I loved it. He has always accused me of being too critical of the school personnel, seeing them as incompetents, and overexaggerating their behaviors. Now I had to control myself not to say to him, 'I told you so.' But I said nothing. Finally, he asked, 'Why are these people so defensive?' I said, 'I don't know about them, but I do know this. When I'm defensive it's because everybody wants me to do something, and I don't know what to do.'

By the meeting's close the allocations of responsibility had been made, and Robbie's IEP for the next year had been discussed, paving the way for its smooth development at the actual IEP meeting. At the pre-IEP meeting, the identity of Robbie's fifth grade teacher was also disclosed. Mary was pleased with the school's choice of a teacher for Robbie's class, having met this woman previously at in-services courses on Chapter 766.

The funny thing about those courses is that usually the teachers who came to them were those who were already doing things well in their classrooms. The teachers who needed it never came. It was encouraging to feel that from the beginning this woman would be very receptive to Robbie being in her class.

But on the first day of school, I got a call from his tutor, the same one who tutored him last year, telling me, 'Robbie won't do anything I tell him.'

> I said to her right away, 'Let me tell you something. Robbie is going to have a good year this year. I don't know who's going to help him have it, but I do know that he is not going to be abused; he is not going to be pressured. He is going to learn just the way he should learn--in a nice, relaxed atmosphere. He is going to have a good year this year. And so is his mother.'
>
> I figured we might as well get the air cleared early in the year and not let things drift. That has been my position ever since. As much as I hate to do it, I found I must set some limits early, often, and everywhere.

This woman had further problems managing Robbie in his tutorial sessions. In November, she started once again to call Mary to complain. In protest over a mid-day phone call, and the lack of any plan to solve the problems, Mary decided to go to the school and take Robbie home with her. The next day, this woman was replaced by another tutor, who had taught Robbie in the past. Although she was unsure as to why her taking Robbie from school for an afternoon would result in such an immediate response from the system, Mary chose not to ask any questions. She felt it was enough to be able to smile and say, "Finally we had a good year."

9. THE SIXTH GRADE AND BEYOND

Sixth grade proved to be a second academically successful year for Robbie. His progress was steady, despite frequent personnel changes. Mary thinks that speech and language therapy, introduced in the sixth grade, has been the source of Robbie's greatest educational gains: appropriate communication and conversation skills.

In the spring of that year, 1976, everyone agreed that Robbie was physically ready for junior high school. Again, however, the professional recommendation at the pre-IEP meeting was contrary to Mary's plans. The system wanted to place Robbie in a separated special education classroom within the junior high building. Mary had heard negative comments from other parents about this classroom, but her criticisms did not make much of an impression at the meeting. She did make an impression, however, when she said,

> P.L. 94-142 is coming, and it's moving toward the least restrictive prototype. Robbie is in a less restrictive prototype now, and he's successful. I have the documentation of that success on your own forms. And, even if we didn't have documentation, Robbie is living proof of the program's success.

As far as Mary was concerned, Robbie would remain within the regular classroom as long as possible. Although it certainly was not the perfect situation for him, Mary felt that it was still better than any other option, and she was not willing to jeopardize the steady academic

and social progress he was making.

At the subsequent IEP meeting, the Team finally agreed to a mainstreamed placement for Robbie in the junior high, while maintaining his independent block of academic tutorials. The IEP also specified integrated participation in the school's art and physical education programs.

Junior high proved to have its share of enthusiastic, challenging teachers as well as its share of unqualified, unsympathetic teachers. Mary becomes philosophical about her and Robbie's relationships with both types.

> It seems that every teacher who Robbie and I have had trouble with, other children have had trouble with also. And, conversely those who accept Robbie and do well with him, have a wonderful reputation with the other students. So the whole situation is just exaggerated by Robbie's handicap. But you see, P.L. 94-142 gives me a way to approach resolving problem situations, when in regular education no one has any idea what to do.
>
> For example, Robbie had a physical education teacher who had a lot of complaints about him at first. He found that Robbie was hard to manage in the group, and continued to say, as others before him had, 'Robbie won't do what I tell him to.' I said to him, 'Well, don't worry about that because I will get you some help. He has to have adaptive physical education, or he has to have some kind of physical education, and if you can't manage him in class on your own, I will see that the school superintendent gets you some help because that's Robbie's right.'

> When I mentioned the situation to the Guidance Department and the principal, their response was, 'We can't provide an aide for everybody who doesn't do well in a gym program.' All I could say was, 'I know and I appreciate that. That's a serious administrative problem. But we do have to do it for Robbie. How you do that administratively, I don't know, but it has to be done. If you want me to, I would be happy to talk to the Special Education Department.'

In the end, the gym teacher asked for a chance to try teaching Robbie on his own for a bit longer; he thought that with time, he could manage.

Mary also realizes that the best teachers are being driven out of the school system, replaced by people who will accept a heavier student load because they are less meticulous in their prepartion.

> He lost his excellent speech and language therapist; she was overloaded with cases. That's what the school administration is doing, they're crowding the specialists' schedules so that the therapists who really do prepare individual lesson plans are overworked. Then they hire people for whom a loaded schedule isn't a bother because they're not going to do all that preparation anyway. Standards get lowered while the school system pays the same money. That's what worries me. The school pays the same money as before but they don't get the same quality. Robbie doesn't get it, neither does the school nor the taxpayer.
>
> You see, P.L. 94-142 makes it impossible to dump kids. That's wonderful...but it doesn't address quality. That's what the parent has to do--address the quality issue.

10. REFLECTIONS ON MAINSTREAMING

After two years in junior high, Robbie was nearing age sixteen. The Guidance Department and the Special Education Department counselors agreed that he should move on to high school, and that the next six years should be taken into consideration in their educational plans for him. At the IEP meeting, Mary spelled out several reasons for her opposition to this plan including the facts that the system was searching for a new Superintendant and reducing the number of school personnel which caused her to doubt that any promises could be made to hold true for the next six years. She had also observed what she considered to be an unimpressive and inadequate Resource Room program in the High School, and she had read a most recent school evaluation report that indicated poor morale and in-fighting among the high school staff. "I know we are prime targets to be affected by something like that, and frankly, I wanted to avoid it." She was careful to listen to the professional presentations, but in the end, her research and her insistence held out.

Robbie remains in junior high, with an evermore thoroughly mainstreamed schedule, which has grown to include the regular science class. Mary is aware that the solution is imperfect. Robbie sometimes comes home discouraged, realizing the contrast between his own performance and that of his peers.

> Last week, Robbie's phys. ed. teacher did some final assessments with the whole class. Robbie came home looking pretty sad and said to me, 'I don't know anything.' He's becoming more aware; he is also becoming very lonely. He doesn't have any friends, and he's never going to have them in regular education. I don't want to cut out any avenues for him, but by

the same token, I want him to have some good experiences that are natural experiences--a friend, at least. Maybe at the high school level it will be different. Maybe the regular students there are not so threatened by everything and not so self-centered.

Mary also acknowledges aspects of mainstreaming that have had a positive, beneficial impact on Robbie's development.

The dramatic difference mainstreaming has made in his behavior is astounding! He has wonderful models. He has bad models too, but he knows the difference. For instance, he knows a lot of bad words, swears, but he never says them. Listen, that's decision making. I think that's just tremendous. Also, his posture has improved. He used to look awkward walking with his head down, but now I have a hard time finding him in a crowd. He has learned how to control his behavior better, too. Sometimes he has to fight for control and I really feel sorry for him--but he learned that and that's a big step! If he were in a substantially separate class and everybody bit their arm, he could bite his arm, too, and who would care? But if he's in a class and other students don't do that, he knows he can't do it either.

His tutorial program is ideal. He has language development therapy, he's reading--marvelous. But if all that disappeared tomorrow, he'd still have a classroom to go to and be one of the kids. And he loves it. He just loves to be part of that school system. He takes me up to a group of boys who say, 'Hi, Robbie,' and that's about the extent of their interaction with him. But he says, 'There's my gang.' She pauses to sniff, wipe her nose, and laugh, simultaneously. That's the way he sees himself, and I think that's tremendous.

I don't know where Robbie will go or what he will do. But I know what I don't want to see. I don't want to see him in the sheltered

workshop as it exists now. I would like to see Robbie employed in the mainstream as well. What would be ideal follows along the line of a grant the Ford Foundation is providing to train hard-to-employ people. They're just beginning to work with retarded people, putting them right there on the assembly line with their own supervisors and their own counselors. They're right there in the middle of the mainstream of the factory and the people get to know them. I'd love something like that. But it depends upon Robbie. It's going to be a long time before we know just what he can do. I realize it's never ending--the worry. But that's the way with my other child, too.

CASE 2: ANNE

CASE 2: ANNE

1. THE KITCHEN

The drive to the Rossi household leads through an inner city of narrow one-way streets, steep hills and triple-decker houses. Placerville is notorious for its low socio-economic status, teenage gangs, poor education system and citizen apathy. It is like many American cities.

Walking into the Rossi household tonight, as on any other night, means walking into a barrage of family activities. Stage center is the kitchen, where the refrigerator the telephone, and the long, narrow bar-like table are magnets for the eight members of the Rossi family.

Anne, the oldest girl, is the first to leap up and answer the incessantly ringing telephone. Although her speech is less than clear, and the call is inevitably for one of her three teenage sisters, Anne chats gaily for a minute before passing on the phone. She then resumes teasing her dad, "Big Jim," who is yet again showing off Anne's photo from the newspaper, boasting of the three gold medals won at a recent Special Olympics swim meet. "She would have won four," he says without a trace of doubt, "but she missed the gun her first time out." He grins with pride explaining her backstroke form, then abruptly ceases bragging to tease her with a kiss on the cheek. She shoves him away and they're off, insulting each other, laughing together, instigating a commotion.

At the same time, Judy, daughter number two, carefully measures each ingredient of a chocolate chip cookie recipe, asking for a few translations of the recipe's directions. Laura diligently works through a math assignment, occasionally embarrassing an unsuspecting victim with an algebraic question. And six year old "Little Jim" finally consents to going upstairs to finish his own homework, when Grandpapa offers his company to ward off any monsters hidden on the second floor.

It's time for Big Jim to go out and meet his friends; Anne settles down at the kitchen table with a book, deftly camouflaging her eavesdropping by pretending she can read. The cookies are ready for the oven. The algebra is guiltlessly dropped for a more stimulating phone call, and all begins to settle down to a quiet conversation, when Sandra enters from the T.V. room with a pained expression, hand to ear, and complaints of an ache. It's time to look for the heating pad...

At the center of the Rossi home activity sits Elaine--pretty, vivacious, appearing much younger than her forty-one years, and hardly a mother of five. With short brown hair and large chestnut eyes, she laughs freely and often at and with herself and the kids. She easily and instinctively becomes serious when one of her children needs attention--and, they frequently do. Her five-day-a-week job at a local day care center ends at 3:00, but Elaine's day continues: at church functions, her daughters' basketball games, play rehearsals, PTA meetings, PAC (Parent Advisory Council) meetings, homework tutoring, a course or two of her own, and, bowling every Wednesday afternoon with her daughter, Anne, and her friends.

Anne was born in 1961. As Elaine Rossie recalls, the last eighteen years, the main characters emerge as an attractive first daughter and a warm, supportive mother; her story involves each of them learning from the other and growing up together.

> When parents of a disabled kid ask me for some advice, I talk to them about some of the things I've learned by having a daughter with Down Syndrome. I explain the whole process to them--the evaluations, the services, the ups and the downs.
>
> But first, I encourage them to sit down and think about their kid; never mind anything else, never mind any of the tests and all of that. Think about what you know about your kid, and if you could have anything, what do you think would be the right thing, the right program for your kid...and get that settled in your head. Maybe you'd have to go visit some programs until you got some sense of what other disabled kids do. How do you go about teaching a Down Syndrome kid or an autistic kid? What's reasonable? What methods are even out there? Go out and visit programs, so you know what special education administrators and teachers and IEP Team Leaders are saying when they throw terminology at you. At least, for myself, the only way I can understand something is if I put my nose in it and find out what's really going on.

2. A PLACERVILLE COUPLE

Elaine was born and raised in Placerville, Massachusetts, in the same working class neighborhood where she now lives with her husband, her father, and her five children. As she recalls, her upbringing was marked by weekly outings with her large Italian family. Every Sunday was a special day, a time for the entire family to do something together. "Wherever we would go," Elaine recalls, smiling, "Dad would always be in the front of the group with a whistle; he was the leader. We didn't have much money, but we sure had lots of family. And lots of fun!"

Elaine met Jim, her husband, when she was eighteen. She was just graduated from high school and was working as a bookkeeper. They dated a few times before Jim went into the service, and, when he returned three years later, they became engaged. They were married the following year. "The whole thing was such a game to me," Elaine says casually, thinking back to eighteen years ago. "I really didn't know what I wanted out of marriage. I guess I just thought it was time to get married." And so, at the age of twenty-three, she did.

Although Elaine and Jim had little money when they first married, they managed to scrape together enough to buy the house they still live in today. Marriage, according to Elaine, was going to mark the beginning of an ideal lifestyle. She and Jim were working. They would soon be "loaded"--able to go anywhere and do anything they dreamed. But Elaine's idealistic expectations about the fortunes of marriage ended abruptly. Soon after the wedding, Jim

seriously injured his back at the moving company where he worked. The injury left him unemployed and the two of them living on a compensation fee of $54.00 a week. In addition, after three months of married life, Elaine was pregnant.

Like any expectant mother, Elaine dreamed of the perfect life for her new baby. Her child was going to have all those opportunities she herself never enjoyed in her youth. Her new baby would receive an excellent education; she would even be able to go to college if she wanted to. She would never have to worry about money. When Anne was born, she certainly appeared to be the "normal, healthy, terrific kid" Elaine had expected.

> The birth was really miraculous. We never realized the wonder of it all, especially Jim. When you saw those little feet, and those little hands and eyes...it was amazing! It was just a miracle! It never occurred to me that anything could be wrong.

3. DOCTORS AND DOUBTS

Since Jim was out of work at the time, he volunteered to handle the night feedings while Elaine slept. He used to sit at the end of their bed and watch Anne just to make sure she didn't smother beneath the blankets; he worried about her congested breathing. They both did. Can you catch a cold so young? When Anne was four weeks old, they decided Jim should take her to the doctor, just for safe measure. When he returned, he did his best to repeat the unexpected news: "The doctor said we should watch Anne. He said she has some tendencies that mean she might be slow."

"Well, you can imagine how irritated I was," Elaine says, her expression providing ample clues. "All I could think was 'what is he talking about?' Here was this wonderful, perfect, beautiful baby...I knew the doctor must have been crazy!"

Elaine immediately took Anne to her own pediatrician to get a second opinion. During the appointment she did not tell him what the other doctor had told Jim.

> I didn't say a word. At the end of the examination, I said, 'Are you telling me I can go now? Is there anything else you want to tell me?' "No, why?' he asked. And I explained to him what the other doctor had told us. The doctor responded hesitantly, matter of factly. 'Well, yes...Anne does have some characteristics to be watched...but I'm not sure.' The doctor then told me I could have Anne tested 'if I wanted to,' and gave me the name of a specialist at Massachusetts General Hospital. So much for the second opinion.

Elaine kept her confusion, her worry, to herself. All she could focus on was the threatened image of her "perfect baby." She decided to entrust her fears to the recommended specialist.

A week after her hospital visit, Elaine received a letter in the mail. The specialist wrote:

> As you can tell from the diagnosis, your daughter has mongoloid tendencies...Treat her like a normal baby...The future will tell what's in hand...If you have any questions, please contact me.

"Can you believe it?" Elaine exclaims, shaking her head in anger and disbelief. Her eyes scan the letter one more time. "He sent a letter to inform me that Anne had Down Syndrome! He didn't even call."

Elaine continues, speaking more quickly than is customary for her.

> I was too upset even to be angry; I just didn't understand. I went right back to my doctor and sat in his office and cried for two hours. I asked him, 'does this mean she is going to die?' And, I'll never forget his response: 'You know,' he said, 'the Kennedy's have a child like your Anne. I even know a mongoloid kid who graduated from high school.' I asked myself, 'What is he talking about? Is he just trying to get me confused? Does this mean she can't go to school like regular kids?' You know, at no time did the doctor tell me that Anne would be mentally retarded.

Elaine's voice stops only long enough to reload.

> My mission from that moment on was to take the Dr. Spock book and make Anne do everything at the age he predicted. Every night after dinner, Jim and I would sit in the den and when it was time for Anne to crawl, we'd sit on the floor and Jim would take the front, and I'd take the back and we'd go round and round the room.

Elaine bangs on the table to emphasize the rhythm of this activity.

> My goal was to march Anne into the doctor's office when she was a year old and say, 'There, now what's wrong with my kid?'

All the while, Jim remained supportive. If the news of his daughter's condition distressed him, he hid from Elaine any fear or sorrow he might have felt.

> Jim kept telling me it would be all right. 'Anne is happy. She laughs. Don't worry about it. It will be fine, you'll see.' He knew I was really upset, but he kept saying, 'What are you worried about? She's a beautiful kid!' He tried so hard to be supportive, but he didn't realize the implications. Neither did I. We were both so ignorant.

Elaine believed she was the only mother in Placerville who had a baby with Down Syndrome. She did not know another parent who she could turn to for advice or depend on for support, someone who had been through this all before. She knew of no other parent who could help her work out her own confusions, who could reassure her that everything would be all right. Since the responses from the professionals were unsatisfactory at best, Elaine decided to assume full responsibility for finding out more about Anne's condition. She felt she had no other choice.

Not really sure of where to look or what to do next, Elaine began by scanning the newspapers and rummaging the library for information about Down Syndrome. Whatever she found, however, neither eased her mind nor helped to sort out her confusions. The resources she was able to locate only intensified her concerns.

> Everything I read explained how kids like Anne would die when they're eight. They would use terrible terminology, words like 'idiot.' I must have called my doctor every week, always asking him, 'Are you sure Anne's not going to die?'

At the same time, the social tension, the public pretense, was beginning.

> No way was I going to tell anyone that there was anything wrong with Anne, because they were going to see that there was nothing wrong with her. I told Jim I would rip his tongue out if he said anything to anybody. I don't know why, but I didn't want her labeled. I kept putting off telling my family, you know, for foolish reasons. I didn't want them to pity me. And, my sister was pregnant at the time, and I didn't want her to worry.

It would be another year before Elaine would even begin to feel comfortable enough to talk about Anne with anyone besides her own husband.

> By the time I told the rest of my family, I was slowly learning to become comfortable with it. I could sit down and tell them what Down Syndrome meant; I could really talk about it. I certainly didn't know everything, but I could say more than what the doctors first told me.

The doctors continued to be far from helpful, only offering the "don't worry" kind of advice. Nothing Elaine read gave her enough enlightenment, or explained to her exactly what Down Syndrome meant. Elaine continued to worry that her eighteen month old baby was going to die. And now she was pregnant again. She was frightened about the birth of her second child--what were the chances that her second baby would have the same problems as Anne, whatever they were?

4. COMING TO TERMS

Any worrying Elaine or Jim may have done about Judy, their second child, quickly dissipated when they carried her home from the hospital. This time they were assured their baby was a "normal, healthy little girl;" and this time they could believe what they heard. With a second child, Elaine could compare both baby's responses, and begin to get some of her information firsthand. Seeing Judy grab a bottle out of Elaine's hand, or attend to the sights and sounds around her, demonstrated clearly the relative slowness of Anne's responses, the differences in Anne. And, now that Anne was two years old, and without any speech, Elaine could see that she needed help. She wanted information, specific information on her daughter's problems--if she could just figure out where to start looking.

She began by calling local colleges, explaining that she had a child with Down Syndrome, and that she wanted to learn how to teach her. A person, a book--anything would help.

After a week on the phone, Elaine was put in touch with the Greater Boston Association for Retarded Citizens (GBARC). She asked, as she had with every organization she called, to be put on the mailing list.

> Soon, I started receiving all sorts of literature. For example, GBARC would send me this material on retardation and I would look at it and say, 'Nothing for me this time.' I still didn't realize that retarded kids had anything to do with me.

Elaine smiles now at her naivete. Without a definition, a place to start, or any clear sense of the problem, Elaine's searching didn't seem to be getting her very far.

Jim, free to spend a great deal of time with Anne during those early years, developed a particularly close relationship with her that is maintained today. But while Jim enjoyed playing with Anne, he was unable to convince Elaine to stop worrying about the problems their daughter might develop. After three years, Jim returned to work and, in spite of his support, Elaine still found herself confused, frightened and alone: "I spent a lot of time feeling sad. I was really heartbroken. I tortured myself thinking of all the things Anne would never have." Elaine imitated herself crying and moaning, "she won't have this...she might not get married." And yet, her feelings were changing more dramatically than she knew.

One evening, when Anne was almost three years old, she was lying on Elaine's bed. Somehow, for reasons she still cannot explain, Elaine saw her daughter in a significantly different way than she had become used to.

> All of a sudden I said, 'What the hell am I doing? I'm moaning and groaning and this kid is laying next to me saying ooooh... aaaah...and she's happy and smiling and loving everybody. This is ridiculous! Jim is right!' Here I was spending the first three years of her life feeling sad, and my God, I enjoyed her so much. I asked myself what I don't like about her today? There's not a thing. She's wonderful! She's a pleasure to all of us; she's happy. I started developing that kind of an attitude...My grieving period was over.

Elaine cannot identify one particular incident or occasion which caused her change of attitude. Time alone, she suggests, was instrumental in letting her anxieties subside. Even with all the services available today, Elaine believes most parents experience this sort of grieving period.

> Services are here now, and so it's not the same kind of a search and lonely feeling as it was almost twenty years ago. But you still need some time to absorb and learn to deal with accepting your kid.

Years later, Elaine was to offer her services as a resource parent through the Association for Retarded Citizens to give younger parents the benefits of her own early history with Anne. "I'd go to visit a new parent and say, 'look, I know what you're feeling. Go ahead and cry. Cry your eyes out...I'm just telling you that it will be o.k. That feeling is going to pass.'"

Elaine sits silently for a moment, thinking.

> You know, something interesting, I found that the professional people I met were much more influenced by their doctors than were people who were more ignorant about the whole thing, like Jim and myself. We didn't have any of this information, we were only looking at this baby of ours, and that's where we were getting our information from. Up to then, the literature about Down Syndrome was very depressing. If we had been very learned, our attitudes might have been quite different.

5. A TURNING POINT

Around the time Elaine was coming to terms with her own feelings about Anne, she received a postcard in the mail from Boston University. The postcard was a notice inviting her to attend a series of workshops for mothers who had children with Down Syndrome. Elaine admits she could have received fifty of these notices a year before, but given her state of confusion and her tendency to deny, she would never have responded to them. They wouldn't have applied to her then.

Elaine identifies the workshops at B.U. as a benchmark in her becoming constructively involved in securing services to meet Anne's needs. She recalls the hours spent at the workshops with fond and vivid memories. Even today she remembers the names of the seven other mothers who attended, the stories they shared, and the transformation of her own feelings.

> In the first session, we went around and shared our experiences: How did you first learn about your child's disability? What did you find out? How did you feel about it? I was so starved for that information! Just to hear another mother say that her kid was a Down Syndrome kid, and that one term meant this, and that another meant that. All this information meant she was retarded. I remember thinking 'retarded?', and my mind started clicking....I was ready to hear it all.

> All of these women had experienced something similar to what I had experienced...yet, each one had a different story. So many of the mothers had been advised by their doctors to institutionalize their kids. I realized how fortunate I was, and momentarily, even thanked my doctor. At least he had never mentioned

institutionalization. Just to hear the other mothers talking was a real burden lifted off my shoulders. Just the fact that they knew...other mothers knew what I felt. I didn't have to explain. I didn't have to try to find words...they knew what I was feeling.

The theme of the workshop was 'O.K., now it's here, so now what? What are we going to do?' Older parents could tell me what to expect; they could give me some answers. And I had a million questions. They talked about how it was important to enroll your kid into a nursery school at a young age. They also explained how you could become involved in organizations which focused on securing services for these kids.

I learned so much. And I realized how much more I had to learn! It also made me hope that no other parents would have to go through what we had all gone through. It made me want to start helping other parents.

After that, I left with all kinds of work I wanted to do. That really was the beginning of my involvement. I left the workshop with all kinds of energy and excitement and enthusiasm. I finally felt direction, purpose. That was the first meeting I ever went to in my life, and I haven't stopped going to them since.

6. THE CAMPAIGNS OF AN ACTIVIST

a. Establishing a Preschool

Heeding the advice of the more experienced mothers from the workshop, Elaine immediately began to search for a preschool for Anne. Because Placerville did not offer any preschool services for special needs children, Elaine began finding out what was available elsewhere--a way of operating which soon became second nature to her.

Elaine's first step was to enroll Anne in the diagnostic summer program at Boston University, where the parent workshop had been run.

> Of course they provided no transportation then. So, every morning all four of us would drive over to B.U. At that time, I was pregnant with Sandra, Laura was a baby, Judy was two, and Anne was three. Anne was petrified of elevators, and the program was on the eleventh floor of the building, so, every day we'd walk up and down eleven flights of stairs!

Despite the rigors of reaching the program each day, Elaine was thrilled with the eight week opportunity it provided both Anne and herself. Through an observation window, she was able to witness an energetic staff, equipped with a variety of bright, colorful materials, working with Anne and other kids who had problems like hers. Elaine could also watch Anne's interactions with other kids, and she liked what she saw. Anne was in a school program; Anne was learning. "From the moment I first saw that program, I knew Placerville had to have one like it."

After what felt like an endless sequence of inquiries with no satisfaction, Elaine finally located an appropriate preschool, not in Placerville but in a neighboring community, where there was a space for Anne to occupy in the fall.

After a few observations of this new preschool classroom, Elaine felt satisfied that Anne's needs were being met in this setting. She was still dissatisfied, however, that the program was in a neighboring community, with nothing provided in her own city. She became more determined than ever to see that, in the following year, Anne's needs would be met in a Placerville preschool.

There was so much to be done--meeting new people, learning the operations of an organization, and, most importantly, mapping out plans to establish a Placerville Association for Retarded Citizens, for with that support, the preschool goal seemed more attainable. In very short order, Elaine and another mother assembled a small group of parents who would provide the nucleus for the Placerville ARC; Elained served as secretary to this new organization.

Through the Placerville ARC, the group worked diligently to set up a preschool in their own community for the following September. The Greater Boston ARC offered to provide the staffing if the parents could come up with the facilities. The local mental health association provided minimal funding--just enough to pay for janitorial services.

> We went from church to church looking for some place we could use. We'd talk to the directors and make a presentation about the kids. After a very long search, we finally found space in the Baptist church. Our husbands went down and washed the floors and painted the walls. We all worked together to get the program set up.

They made it, and Anne started preschool in Placerville in the fall of 1965. From the first day of the program, the relationship between the teacher and the parents was strong and mutually respected. The teacher had established a weekly mothers' group in which questions and concerns about all aspects of the program were discussed openly. The parents, and Elaine in particular, were satisfied that the program was what their children needed. They felt that the class of children complemented each other well--they were a group, with similar needs and similar problems, and together they would gain whatever skills they were capable of learning.

b. The Battle for Recreational Services

Resting on the laurels of their first successful venture wasn't possible for the Placerville ARC--there was too much else to accomplish. Summer was approaching, and the Placerville chapter was easily convinced to work along with GBARC in their next endeavor: attaining summer recreational programs for retarded children in Placerville. The parents felt that June through August was too long for their children to be without any program. The playgrounds offered recreational programs for all the other children; a summer recreational program should be available for retarded children as well.

The parents presented a request for a summer recreation program to the town's recreation director. "We tried it before, and it didn't work," was his only response, but this was unacceptable to the members of the ARC's. The groups had done their research and were able to detail for him why they believed the earlier program had not been successful: facilities were virtually nonexistent, or at best, inadequate;

the program had been held outside in the hot sun, without a tree in sight for cover; in short, from the start there was no incentive to send a child to the program.

The ARC parents were convinced that they were better informed, better organized, and more determined than parents had been earlier. Their children would have the opportunity to enjoy a summer recreational program with the equipment and structure they needed, like every other child.

With obvious pride, Elaine explains the group's strategy to establish these summer services.

> The battle for recreational services turned into a big event, a fight which lasted for two years. We got quite an education. First of all, the director did not want such a program to be established. He kept telling us there were not enough people interested in it. So we would leave his office and go out and get a list of names of people who wanted summer services and bring the list back to him. Then he would say, 'there is no facility.' So, our next step was to find space for the kids. Then, he told us there was no money available. After talking to various people, we learned that a city could get a 50% reimbursement from the state if it offered a program, so we presented that information to the director.
>
> A large part of our learning what to do and how to do it was by trial and error. We would go from room to room talking to all sorts of people. After a long time, we would find out who was responsible for what. We learned which politicians carried what kind of weight; if we talked to so and so first, we wouldn't have had to waste two hours talking with someone else. I guess what we learned during those two years was how to lobby.

> Our goal was to have something in the newspaper every week. If someone was giving us a check for even one dollar, we would call up the press and have the cameras there! We felt the exposure would give us more power. When we went to the City Hall to confront the Mayor, we would call everybody we knew and tell them to come so we could fill the hall. We called all of our neighbors...even my sister came, and she lives an hour away! We made sure the legislators all knew the ARC was coming!
>
> After two years of persistent effort, legislation establishing the summer recreational programs was passed. We won...but we didn't stop for a celebration. We were already off on our next campaign.

c. The Statewide Preschool Movement

The Placerville ARC was, at the same time, battling for preschool programs for special needs children in every community across the state. "At the time, and remember this was 1964, we thought all retarded kids should have the opportunity to go to preschool, not just kids whose parents get involved." So, with as much energy and conviction as they were demonstrating in their battle for recreational services, the group was tackling the challenge of getting another mandate formalized. Meetings were held at least weekly; Elaine's phone did not stop ringing.

> We were so excited to jump onto the bandwagon back then; it was a good place to put our energy. I remember one parent saying, 'I never thought I would be saying this,' when we used to tease each other about who had the smartest retarded kid. We could even joke about ourselves and our kids now, when only a few months earlier a lot of the parents were where I had been a year ago.

As exciting as these two years were for Elaine, she admits they were also draining. She now had a family of three children, with a fourth on its way. Jim was back at work. "The kids would be crying, and I would have all this work to do and meetings to prepare for. People would call and call and call. I was exhausted, but I enjoyed it!

By the time Anne was ready to enter the public school, Elaine had already been instrumental in establishing a preschool program in Placerville, she had lobbied furiously and effectively for special needs summer recreation programs across the state, and she had become centrally involved in a statewide effort to mandate preschooling for retarded children. Her commitment to parent activism was well under way.

7. ANNE AND THE PUBLIC SCHOOLS

Anne's next step was a major concern for Elaine. The preschool parent group wanted to know exactly when Placerville was planning to provide for their children. Realizing the parents' concern about their children's educational future, the preschool teacher invited the Placerville Special Education (SPED) Director to speak to the group of parents, to explain what the city had to offer Anne's group.

> It was all very suspicious, Elaine recalls. The first thing the SPED Director said to us was, 'On the first day of school you just put the kids on the bus which will pick them up everyday, and they'll be driven to school.' That was it! We asked him, 'Where's the school? Who's the teacher?' I remember Jim asking, 'Why can't we take these kids to school on the first day, like we do with all our other kids?'
>
> The SPED Director tried to answer our questions diplomatically, but he really wasn't providing any information, and he obviously didn't want us to go into the school. He ran a very tight ship; he liked everything under strict control--his control. In his own way, I suppose he was a very dedicated man, but, of course, he began 30 years ago. Attitudes had changed since then. At least, I think we were a different group of parents with different attitudes. Before, the attitude was 'parents should be grateful that kids went to school at all, even for two hours a day, and he's a saint for providing that.' But now our attitude was different. We felt strongly that our kids should get what everyone else gets. That's just how it should be.

The meeting with the SPED Director gave Elaine reason to worry. She would now respond, however, in what was becoming typical fashion for her: if the SPED Director refused to provide specifics about Anne's program, then

Elaine, with another mother, would go investigate for herself. What they discovered was disheartening.

> We must have gone in the back entrance to the school because we ended up walking through the basement. We found the classroom right next to the boiler room! We opened the door to the classroom and it stunk, it was dark, it was dreary, and there was no equipment in it. We just sat in the back of the room, horrified; I mean horrified!
>
> We left there thinking, there's got to be something else. So we went to see what the next town had to offer. The classroom was wonderful! It had toys, good lighting; it was cheery and clean. We went back to Placerville immediately, got on the phone, and called all the mothers whose kids were to be in that class next year and told each of them to go visit the class. Needless to say, everyone was really uptight about what they saw.

There was no argument; something had to be done. Elaine and the other mothers scheduled a second meeting with the SPED Director to let him know how upset they were. He told them he would see what could be done. When they met with him a third time (at the beginning of the summer), he presented news they were pleased to hear. The school they had visited was going to be renovated during the next two months and made into a separate program for special needs children; their children were to be guaranteed clean, bright classrooms--with materials.

Elaine and her group's success in bringing about changes each mother believed were necessary resulted from a strategy that was to be repeated again and again in the future. It was a simple strategy, tactfully resting on common sense and

reasonableness. It was a strategy which Elaine recalls now with amusement.

> Every year we would come out with a list of complaints, put them in writing and send them to the SPED Director. This would give him advance notice of our specific gripes so that by the time we met with him, some of the necessary changes had already begun to take place. It was a crazy game we all played.

What Elaine called a "crazy game" was in fact a successful strategy that relied fundamentally on being well informed, staying in touch with what actually happened in the classroom on a daily basis.

"We gradually developed a network of 'spy' teachers. We would uncover a whole bunch of things that our spy teachers told us about. As Elaine explains their detective work, her expression turns crafty.

> Our spy teachers told us, for example, when a kid had been terminated from school. According to the law, that was illegal. Just because a kid is retarded, the school has no right to expel him. And that's when our work began. We then got as many contacts as we could to see what else was going on. We would always try to analyze what the hell was happening--either something was wrong with the teacher, or there was another kid coming into the classroom and they needed more space.
>
> Once we were sure we had all the information, we never confronted the superintendent face to face with what we knew. That wasn't our method; we tried to be more diplomatic. We wrote letters explaining the situation; we explained that we knew what was going on, that according to the law what was being done was illegal. By the time we finished writing all those letters, there was really nothing the superintendent could do. We knew it was illegal; he knew it was illegal. Eventually everything would work out. But it took a lot of time. It always does.

8. LEGISLATIVE SUPPORT

In the early 1970's, a series of legislative actions transforming the educational rights of disabled children occurred in Massachusetts. The first of these, the 1972 Mental Retardation Regulations, limited its scope to the children labeled retarded. The 1972 Regs stated that every retarded child was entitled to a thorough evaluation at the start of every school year. In addition, each evaluation would be conducted by a team consisting of four professionals: a social worker, a physician, a school representative, and a psychologist.

Prior to the 1972 Regs, evaluations were merely offered as a token to those parents who insisted upon them, and, not surprisingly, Elaine had been one of those parents. But, the evaluations had proven worthless, a waste of time. Elaine knew she was no psychologist, but it did not take her long to determine that the whole procedure was useless.

> There were terrible injustices done with those fifteen minute evaluations. Children were grossly misplaced. They were placed more on the basis of numbers and space than on what their needs were. In Anne's case, the problems were pretty clear cut, so she didn't suffer. But if a kid had more unusual problems, he would suffer tremendously. I knew of one kid who was diagnosed 'retarded,' and it turned out that he just didn't speak English! He was Spanish!

The 1972 Regulations led to evaluations that appeared to be more clinically expert, but no more satisfying to Elaine and her colleagues. She felt excluded from a process--determining Anne's educational needs and potential--that she herself had done so much to initiate.

When Massachusetts Chapter 766, in anticipation of P.L. 94-142, ensured parent involvement in the determination of the individual education plan (IEP), Elaine's hopes and enthusiasm sharply revived. To be let in at last on the public school's programming for Anne! As she recalls, however, her eager expectations didn't even survive the first IEP meeting.

> At that first IEP meeting, they tried to set it up as threatening as possible. I walked in, and the teachers and administrators were on one side of the table, and I had to sit alone on the other side. I asked, 'Where does Anne stand academically? What does she need?' And they said nothing. Anne hadn't gotten her period yet, and I thought she should have something in her ed plan dealing with health issues and the facts of life. They said, 'No problem, if anything should happen at school, we'll just send her right to the nurse!'
>
> The teacher was so intimidated by the others at the meeting that she wouldn't even speak. She kept looking over at the SPED Director, and it was pretty obvious that he didn't want anyone to talk. What they were doing was writing up ed plans to fit whatever they had available in the system.
>
> Before this time, there were no speech programs in the school at all; I have always taken Anne to private lessons. Once the law came, I demanded that speech be a part of the program. They tried to convince me that Anne didn't really need speech. Can you believe it? I didn't sign the plan. It was ridiculous! There was nothing to measure anything by...no specifics. And all the parents had the same experience. Our kids spent the time with babysitters while we spent the entire afternoon at the IEP meeting. It was such a farce!

Elaine feels it's unfortunate that while she has gained increased awareness of the law and its mandates over the last five years, the quality of the IEP meeting process in Placerville has barely improved; she still finds she

is unable to sign the first draft of an IEP. Experience, however, has left her unable to feel intimidated by the proceedings. Placerville has learned that she takes the product of those meetings, the IEP, and uses it for Anne's benefit; she takes what is written very seriously.

Sticking to the IEP as written, however, does not begin to solve all of the problems Elaine has encountered in the last five years. Some are endemic to the Placerville school system; some are the special burden of parents trying to see that services for their special needs children are actually provided as promised.

"If only we had a good school system...then everything would be a lot easier." Like many other working class communities, the Placerville school often runs short of even the most basic "educational" commodities.

> Last year, they had physical education class in the girl's gym. There was no heat in that room, and there were maybe two light bulbs that worked. Now that's deplorable. Heat and light bulbs are not services that are typically written into educational plans. These should be considered givens for running any school, not rights for which parents need to advocate.

Speech therapy <u>is</u> a specialized service, one which the educational plan provides for. However, plans have repeatedly been violated.

> They did not have a speech therapist, simply because they hired one and she left for another job. O.K., now I can go through this whole big court process, but to me it's stupid. By the time I would be finished, with all the time it takes and all the money, they would have hired another speech therapist anyway. So, we just keep writing letters and complaining about it.

Even when speech therapy has been delivered as promised, Elaine has not always been satisfied with the conditions under which the sessions were run.

> Two years ago, I was finally satisfied with Anne's ed plan. Among other things, she was to have speech for a half hour twice a week, as she has had in the past. But I soon found out she was having it in a stairwell! Now, isn't that ridiculous? The speech therapist was offered a classroom on the other side of the building, but she didn't want to keep running back and forth from one classroom to another.
>
> The next year, when we wrote up the ed plan, I said I wanted Anne's speech therapy in a room where there's an electrical outlet, where it's adequately lit, and where there's reasonable noise levels. (So much for not putting light bulbs in ed plans!) I had each and every one of those points written into the plan. So this year, I went to look at the room, and it was like a closet. It was a room, but it was like a <u>closet</u>! And it took the whole year to argue just for that!
>
> My option is to have Anne transported to another school for speech, but that would cut a chunk of time out of her day. This is when I say, 'I don't know. Is it worth transporting Anne to another school for speech therapy? Is it worth it or not? Am I going to argue it?'
>
> So this is where I fall apart as far as really following through. I mean, that's really not right. They shouldn't be allowed to get away with that.

Elaine's most recent efforts have been directed toward the development of a curriculum guide for Anne's program. Elaine would like to see some specific goals mapped out, some sort of blueprint for the program.

There's no appropriate curriculum written for our level kids, so it is totally up to the talents or the whims of the teacher. She can be great and have a wonderful curriculum, then she can go away and another teacher comes in and says, 'I think this is what I'll do,' and does something completely different.

There is just nothing to measure anything by. Goals are not being spelled out. That makes it so difficult for parents to evaluate and decide whether or not a program is right for their child.

9. THE CAMPAIGNS CONTINUE: THE PARENT ADVISORY COUNCIL

Inadequate facilities, violated IEPs, chaotic changes in the curriculum--these kind of problems were too big for Elaine to overcome on her own. She had experienced the power of organized parents in the accomplishments of the Placerville ARC. She greeted with enthusiasm, therefore, the Chapter 766 recommendation to establish a Parent Advisory Council (PAC) at the local level.

Elaine has found, though, that the PAC is like most other committees.

> It's hard to get people involved. It's always the same group of parents; just like with the PTA, you always get the same group of parents attending those meetings. I hate to say it, but I think in Placerville there is a large number of people who really don't care... Most people here don't place a high value on education; they're just really apathetic.

Elaine recognizes other obstacles besides apathy that impede the work of the Parent Advisory Council. The Placerville school system is bureaucratic and underfunded, so that problems parents encounter sometimes seem overwhelming. Organizing a parent group under these conditions is frustrating, yet Elaine maintains a sense of optimism. She recently initiated a school-by-school assessment of parent issues, through which the organization was able to gain exposure and set some goals that responded to concerns from new voices

The many years of involvement in parent organizations allows Elaine an experienced perspective of the PAC.

> For years I've been involved and seen that you take five steps forward and you take four steps backward. You take three more big steps ahead and one great big thing comes and you just feel like you're put down again.
>
> But you've got to stick with it. My feeling is that if people can see setting some goals and meeting these goals, then they want to get a little more involved and they're willing to spend the time.

Yet another complication has arisen for Elaine and the veterans of the Placerville ARC. Chapter 766, which brings together the whole range of disabilities, has undercut the sharp forcus and similar needs that mothers of retarded children in particular shared. "My individual concerns have to get in line and take their turn now," she realizes. "And I've had to learn about and support--and sometimes argue with--the needs of other disabilities."

Elaine believes that the PAC has acquired a certain amount of credibility in Placerville. "We have no power to make the school system do anything we recommend, but my experience is if you keep hammering away at it, you know, eventually something will come of it."

The major frustration for Elaine lies in the lack of support and lack of cooperation of the school administration, particularly the SPED Director. As Elaine discussed him, the rancor in her voice clearly signaled her distaste for him.

> He is important, incompetent and irrational. When you start getting close to an issue where he knows you're right, he'll start screaming and yelling at you. He'll become erratic. I think it's a tactic of his to get you off track. For example, next year the Placerville school district is not

contracting with the preschool for services. Of course the law states that preschool services must be available beginning at three years old. I want to know what they are going to do about it as of 1980.

When I found out about it, I put it on our PAC agenda, and said to him, 'Gee, Frank, what does this mean? I would like to form a subcommittee so we can make some suggestions on preschool plans.' Well, Frank started yelling, and telling me it's none of my business. We ended up getting in this whole argument again about what is the PAC's business. I asked Frank, 'What are you saying? That we can't ever talk about it?'

I don't think I am such an idiot that if he said something couldn't work out because of this reason or that reason, that I wouldn't understand what he's saying. Perhaps I wouldn't agree with him, but at least I would know he had some reasons....All I was asking for is the chance for us to give input.

At times, it seems as though the SPED Director believes the PAC should serve as a puppet for the administration. Elaine is not asking for the power to implement, she is only asking for the right to "monitor and advise." At the end of the 1978-1979 school year, the relationship between the Placerville PAC and the school system remains ambiguous and stormy, frustrating and challenging.

10. ANNE: TODAY AND TOMORROW

Elaine's group work in the Placerville ARC and the PAC has not made her any less attentive to the specific needs of her own daughter. A tremendous amount of her energy goes into planning for, and worrying about, Anne's educational progress--and her vocational and personal future beyond the school years.

Two years ago, when it was proposed that Anne's group move into the junior high school, Elaine was opposed. She was in favor of the group's moving out of the grammar school into the high school, but the reputation of the junior high schools in Placerville was too negative. Poor educational quality, disciplinary problems, vandalism, and drugs were not merely rumors; Elaine had lived in Placerville her whole life and was quite aware of the situation. She was also fully aware of the adjustment problems young adolescents in junior high must cope with, and felt they would have a much harder time accepting Anne and her classmates than high school teenagers.

Elaine's opinion was vetoed this time, and Anne has attended a Placerville junior high school for the last two years.

> The first year Anne's class moved to the Junior High, there were several problems. Anne's group stayed in their classroom all day long--they didn't even go into the cafeteria for lunch. Their teacher was an older woman, 'set in her ways,' who was used to teaching 'educable' kids. She was reluctant to do much of anything outside the classroom with this 'trainable' group, and in class, she didn't seem to be expecting much from the kids.

This year, Elaine reports that there has been a big improvement. She feels it's partly due to the recommendations made by a mental retardation task force of parents, and partly to a new, younger teacher, who is more sensitive to the needs of the kids. Anne is taking woodworking now in the regular woodworking room and eating lunch in the cafeteria with all the other kids. The new teacher has established a close relationship with Elaine and the other parents.

> I will admit that I was wrong and that the Junior High wasn't anywhere near as bad as I thought it would be. Programatically, it hasn't been terrific, but socially and emotionally for this kid, it's been great! She feels quite grown up and she loves going to Junior High. She's very clothes conscious. She wants the rolled up pants, the boots, which I think is good. She sees her sister's friends at school, and they all say hello to her, and that makes her feel good. She can't wait to tell people she goes to the high school.

Beyond high school, Elaine knows that she must find some sort of vocational training for Anne. She is unhappy about the kind of work activity program the system is likely to provide.

> I don't want Anne to do just one job all the time, like sorting popsicle sticks into little bags. She does that now for one period a week, which is fine. But no more. The only reason I allowed her to do that activity for one period was to see if she could follow directions. I just can't see her doing that for five hours a day, five days a week!
>
> Obviously, Anne won't be in the competitive work foce, but there is a certain level she can function at beyond sorting popsicle sticks!

For instance, she is now learning how to sew, and she's still involved with the woodworking shop. I would like her to continue working on those kinds of skills.

I can't tell you for sure what I want to see her doing, but I know I don't want her sorting popsicle sticks the rest of her life. Next year I will start visiting programs and workshops so I have some sense for what skills Anne needs. Come next June, I will be in a better position to sit down and talk about what goals I want to be written in her ed plan. Like I said before, the only way I can understand something is if I put my nose in it and find out what's really going on.

CASE 3: JAKE

CASE 3: JAKE

The Kelley family lives in the heart of a large, diverse, inner-city community. Upon first entering their immediate neighborhood, one is struck by its density, given its narrow streets, steep hills, and triple decker homes. The streets are always used as a playground by young children during the day and not infrequently as a teenagers' hangout at night.

Jeannie and Richie Kelley, both in their early thirties, have often individually expressed their satisfaction with their marriage, a situation that is atypical of many of their neighbors and friends. Jeannie admits freely that as a couple, they have not been without their problems over the years, but they both appreciate their mutual efforts to accomplish an indepth level of communication and attribute the marriage's success to such efforts.

They both also painfully admit that raising three children is no easy chore. Kerin and Jake are five and six respectively; Brian is the baby at two and a half. Each of the three is an extremely appealing child--a child photographer's dream. Yet all three also exhibit a variety of demanding, attention-seeking, uniquely different behavior problems, which makes many days long, laborious and difficult to survive, especially for Jeannie who rarely finds respite from their care.

It is the oldest boy, Jake, who has been determined however vaguely, to have learning problems. Exactly what those problems are has yet to be assessed adequately. Both parents share snatches of observation and suspicion in the following characterizations of his developmental history.

When Jake was two and a half, it was evident that his gross motor and reflex development was slow, given the frequency with which he would fall on his face and do nothing with his arms to break the fall. As a result, his front teeth became cracked and broken. His four top teeth were eventually removed upon a doctor's recommendation in order to prevent infecting his second teeth, leaving Jake with a large gap in the front of his mouth. This added to his appeal, but his parents suspect it perhaps added insecurities as well.

Jake's speech and language have also been slow in coming. When his sister, Kerin, born a year after Jake, developed clearer and better speech than he, his parents had evidence that there was some delay, but were unsure what to do about it. They also noticed that Jake responded inconsistently to sounds--often not responding to those coming from behind him, yet sometimes hearing a whisper in the midst of other loud noises.

Suspecting the problem could perhaps be a hearing loss, Richie took Jake, at the age of four, to the city's school system for a hearing test. Richie watched through a one-way mirror as Jake inconsistantly but often failed to respond to the tester's demands, or even to the sound of her voice coming from behind him. It was difficult

for Richie to watch their suspicions be confirmed, yet the actual results as they were explained turned out to be more vague than informative. He and Jeannie were told that Jake has a hearing impairment in each ear, but that the actual decibel loss could not be determined, because Jake doesn't have the skills to perform the audiologist's test. They were to wait another year, and perhaps by then he would be ready to take the test.

Jake's hearing loss and speach and language delay were of obvious concern to Jeannie and Richie, and this worry was intensified by his behavior problems, which were becoming increasingly serious and consuming more and more of their energy each day.

Jeannie and Richie have described Jake's behavior at times as being "totally uncontrolable," yet so inconsistent as to be difficult to "figure out." Jeannie thinks he is a "closed up kid" who rarely talks about his feelings and has a hard time dealing with them. He will aggress against his parents, his sibilings, and his pets without apparent provocation and often without warning. He is frequently non-compliant, and may refuse to perform skills he can do with ease--for instance, dressing in the morning. And, he will "tantrum:" kicking, screaming and throwing objects--for reasons that continue to elude Jeannie and Richie.

At the age of four, when Jake killed their pet bird, Jeannie and Richie knew they needed to seek outside help in understanding and dealing with their son. For more than a year, Jake went to weekly sessions with Jane, a psychiatrist, for play therapy. Jeannie went to see Jane as often on her own to learn some play therapy techniques, but also to determine methods for dealing with Jake's emotional outbursts

and to talk with Jane about her own past history as well.

Jeannie feels that Jane has helped her gain a better understanding of herself, and that a few play therapy techniques--particularly working with puppets--have helped discover the root of some of Jake's emotional outbursts. Yet, Jake's aggressions, non-compliance and "tantrums" persist, intermingled with his warm affection, easy smile and helpful moments around the house, leaving his parents pondering an enigma they've yet to understand.

When Jake entered preschool, his behavior problems in that setting became apparent early on. He was five years old when this program recommended that he no longer attend, and that Jeannie and Richie take him instead to the New England Medical Center for a developmental evaluation as the first step in the IEP process. Jeannie and Richie to this day are as unsure of what was evaluated when they took Jake to this medical center, as they are of the results from any of the tests. They do know they "would never go back there again." Their discussions of the evaluation are scattered and bitter; they remember nothing being explained to them. They felt as though they had been subjected to professionals whose attitudes were that they were "only parents" which seemed synonymous with "peons" to Jeannie and Richie. They were given credit for knowing nothing.

Jeannie sat in on a psychological evaluation and came away feeling angry and frustrated. Jeannie reports:

> The psychologist asked him, 'what's this?' pointing to her desk. Now I told her that Jake doesn't know what a desk is because he's never seen one. She said he must have seen one in his school, and I told her they didn't

> have desks in his school, it's only a kindergarten. She asked him anyway and Jake said it was a table, so she marked him wrong. That made me so mad! Why didn't she listen to me?

Jeannie and Richie don't know exactly what tests were given to Jake at the medical center, nor did they receive a copy of the results. As far as they were concerned, the whole thing was a waste of time.

But it was soon after the assessments were completed that they were told by the preschool that an IEP meeting was to be held to discuss Jake's educational program. Much later, they complained that they never received a written notice that this meeting was to take place, nor were they informed of their rights under the state and federal laws.

Mr. Sarason, the IEP Team Leader, called to explain to Jeannie what they should expect to occur at the meeting. "But," says Jeannie, "it didn't happen that way at all."

> The IEP meeting was a farce; it was really disgusting. We knew hardly anything about it. We didn't know what was what, who had to come. At first we were even told we were not going to be let in, that we were not part of the Team!
>
> Plus, there were so many hassles. Our babysitter called up at the last minute and said she couldn't make it, so Richie went over to the school first, looked over all the paper work, and talked to Mr. Sarason. When he came home, I went to the meeting. I was pretty nervous, at first, but then I started to get really mad when I heard all the stuff they were saying about Jake. I tried to sit there smiling nicely and behaving, but I had to keep saying to myself, don't blow your cool.

The meeting lasted two hours. Jeannie sat and listened to the preschool staff read their assessments of her son; all she could hear were the negative things they were saying--the seemingly endless anecdotes of his behavior problems, and the things he could not do.

> I had no idea that I could turn around and say I want to take a break! They kept saying that he needs a one-to-one; they were recommending a private school. I had no idea what was going on. Then it sounded like they were talking about putting him in the hospital permanently. I was saying to myself I can't believe that they're talking about my son like this. He doesn't need that. He needs to be interacting with other kids with similar needs. I knew Jake needed special help, but I didn't know exactly how much. I figured once we got him into a good program, then we could decide if he needs more or less help. The teacher will be able to feel him out and figure out what's what with him. They kept asking about a private placement, and finally I looked at them and said, 'Hey, he's not retarded and he does not need to have somebody there <u>constantly</u> for him. He <u>can</u> do for himself if he's <u>made</u> to do for himself.'

Jeannie became more and more angry listening to these strangers characterize her son and continuously imply that he was "retarded." Finally, the team asked for Jeannie's reaction and recommendations.

> I said I thought I was coming here to listen to what the professionals had to say. Then I thought I was supposed to take it all in, figure it out in <u>my</u> head and say O.K. I agree with this, this, and this. And if I don't agree with something, O.K. It was blocked out. But you have said nothing about what you expect him to accomplish.

Feeling distraught about the meeting's content and proceedings, Jeannie was grateful to hear Mr. Sarason characterize the preschool's assessments as inadequate and unsatisfactory. Mr. Sarason made the recommendation for diagnostic placement for Jake: a six-week intensive evaluative program that would determine Jake's strengths and weaknesses, and prescribe the goals, activities and learning situation which should be provided to meet Jake's needs. Jeannie agreed immediately to such an option, feeling relieved that Jake would not be sent to a private school, and that a solution to what Jake needs could be forthcoming.

But, relief didn't last for long.

It was after the IEP meeting that Richie found himself browsing through some pamphlets while waiting in line to cash a check at the supermarket. Here, he found a booklet explaining that parents and children have rights under Massachusetts' Chapter 766, and the federal law, P.L. 94-142. This was a new and intriguing piece of information, which prompted him to contact the producers of the pamphlet right away. This group, the Federation for Children with Special Needs, is a parent-run information advocacy center, which among other services, periodically offers workshops to inform parents of their legal rights. Richie attended some workshops and learned all he could about the law, but the information wasn't enough to help him deal with the pragmatics of the school system over the next nine months. Jeannie reports:

> According to Chapter 766, whatever a child needs, the school is supposed to provide. According to Mr. Sarason, when I asked him a few weeks later how the diagnostic placement was coming, he said 'we can't do it.' He said our city didn't have one available for Early Childhood kids this year; it was only

> for grade two. I said, 'What? Grade two is too late. You should have that program now, when the kids need it! He said, 'Believe me, I know! But they don't have one for Jake this year. I wish there were something I could do to help.' So here we were, without an ed plan and without a program.
>
> What we ended up doing was letting Mr. Sarason, who had met Jake a few times, sit down and write out the IEP. Then he gave it to us to look over and add anything we could think of. We added a few things, but this was the first time either of us had ever seen an ed plan.

Then Jeannie reports that Mr. Sarason took Richie to observe a few Early Childhood classrooms in an attempt to find one that looked appropriate for Jake. When that was accomplished, Mr. Sarason wrote it into the IEP and sent it to the main office in Boston for approval.

Six months later, after nine months of sitting at home with no educational program, Jake's IEP was approved. Jeannie, Richie, and Mr. Sarason are convinced that Jake's IEP sat on top of someone's desk, somewhere, under a myriad of other papers just like it. They suspect it moved around from desk to desk, but no number of phone calls any of them made had any impact in speeding up the process.

Their criticisms over what they've characterized as this city's chaotic inefficiencies are fierce, and painfully exacerbated by what came very close to becoming total mistrust on Jake's part towards his parents, whose promises that he'd be going to school "soon" remained unfilled for so very long.

CASE 4: DERICK

He jumps out of bed in the morning before his eyes have yet opened, and his skinny little legs lead him down the hallway toward his parents' bedroom. His mother hears him when he first begins to stir and is out of bed in an instant to meet him outside the bathroom door. Already he is greeting, hugging, talking as she kneels to his height for a hug while she checks: Is he wet? Does he need a bath? Can we start the day with a success on the toilet? She points his nimble body towards the bathroom door. Together they cross its threshold to perform the first of the day's activities.

At six years old, he not longer takes Ritalin. Thus he is constantly moving, incessantly talking. They descend to the kitchen, he questioning, she answering. The topic is unimportant. She read somewhere about the importance of stimulating language, and this she remembers at 7 A.M.

He must be kept busy while breakfast is prepared. She directs him to set the table and, with one eye and hand on him, the items reach their destination. Simultaneously, she prepares his meal remembering automatically which foods to avoid--those he is allergic to, those that cause his bouts with diarrhea. She turns for a moment and hears him toss the plastic cups and bowls under, across and around the table. He climbs down from the chair and runs into the next room. She silently gathers the equipment and the boy, straightens the kitchen scene, and serves breakfast.

She sits beside him while he eats. He doesn't need hand over hand guidance in using his utensils anymore; he has mastered that skill. But he does need reminders--to use his spoon (not his fingers), eat slowly, chew his food, take small bites and wipe his mouth. Throughout breakfast, he grabs, kicks, talks, spills, eats, drinks and grins. She ignores, prompts, redirects, demands, assists and praises. He eventually learns.

The rest of the family begin to rise and join the kitchen activity. They are on their own while she and he climb the stairs to dress for the day. Piece by piece, his clothes are donned. She starts him off, he finishes the task, ever-so-slowly progressing to accomplish more on his own each day. She remembers being told not to talk to him while dressing: "He must focus on what he is doing--NO DISTRACTIONS." She cheats a little as he struggles with his T-shirt, answering a simple question, but not without feeling a familiar tinge of guilt. But then she must grin, in spite of herself, as his arm pops through where his head should be and he struggles to make it right. She redirects his arm, before they are interrupted by the sounds of the teenagers calling for her help to get them ready before they depart for the day.

She descends the stairs quickly to retrieve the gym shorts "lost" in the dryer, and a crutch from under the living room couch. She admonishes her broken-ankled son for misplacing his crutch; he and his older brother seize an opportunity to make her laugh and kiss her cheek before they race out, less than cautiously, to make their way to school.

Dad passes by to relay his day's plans. He will attend class after work; she will keep dinner warm. They have merely a moment before he, too, is off for the day, headed north to the city.

She returns to find her youngest in the bathroom, with a sink on its way to overflowing and toilet paper roll stuffed into the flushing toilet. She counts to ten...angry and frustrated: at herself for leaving him unattended and forgetting what he would do; at him for needing so much attention, structure, energy.

Back to task: it's time to put his pants on. She methodically directs his feet into the legs, and prompts him from the hips up.

The phone rings...and rings...and rings.

He earns a quick hug as she scurries to the phone. His dentist appointment is confirmed; she runs back before time allows him to wander into mischief. She brushes his hair quickly, automatically. Together, they brush his teeth, with her hand over his, carefully, systematically.

She leads him to the toilet one more time before he's ready to leave. But she is too late; he's wet again. With a sigh, she gathers clean clothes to quickly change his pants, but not before he pulls the toilet paper off the wall, drops his shoe into the toilet and toothbrush into the sink.

At last he's ready, sporting sneakers and a grin. She directs him to sit on the porch steps for a moment by himself and wait for the bus to come. She watches from the window, hoping this small lesson towards independence will someday meet success. For the first minute he sits, talking to himself. Then, suddenly, he's off and running. She finds herself close behind him, reaching to stop his small thin frame before he makes it to the street, and leads him back to the steps.

The bus turns into the driveway, late again. They walk to the bus, hand in hand, waving to his classmates. They kiss goodbye, anticipating their reunion in six hours to continue their day together.

She savors her coffee, the paper and the sofa for twenty minutes. And then she rises to deal with the day's phone calls, appointments, housework, errands. They are to be completed before he returns, for when he is there, her attention must be his.

Marcia and Raymond Clarke, both in their mid-thirties, are the parents of three sons. Their teenaged sons are handsome, bright, athletic, congenial. Derick, at the age of six, is active, inquisitive, affectionate, adorable. Their home sits in a wooded area in a suburb south of Boston.

Marcia's six-year-old gives her day the same structure as that of many others whose children are labeled "developmentally delayed," "retarded," "brain damaged," "autistic," "hyperactive,"...the series of labels is endless, and somehow, not so important to the Clarkes.

Marcia's concern is rather with what he needs, can do, and what he will be able to do, someday. Her concern is also with her family and with herself; she worries about the strain a special needs child places on each member, because of the number of different roles each of them is expected to play as a result of Derick's disability.

At any given moment, she has found herself, her husband, and even to some extent her other sons, playing the roles of parent, teacher, advocate, psychologist, speech and language therapist, and even lawyer. And, during many of

these moments, she has felt tired, drained, confused and angry.

Marcia recalls the times she has dreamt about what a pleasure it would be to go to sleep and never have to wake up again--never have to deal with the strain the child generates, and the stresses the outside world has caused or exacerbated. She timidly admits to having, in a most intense moment, contemplated suicide.

> I often say that Derick is my greatest pain and my greatest pleasure. He's the sweetest thing, and when I see that smile, he can make my heart sing the way nothing else in this whole world can. But he can cause a mental and physical pain that I never knew existed. He exhausts me.

When Derick was still an infant, Marcia and Raymond noticed there was something different about him--a slowness in development that hadn't been evident with their previous sons. Continued inquiries addressed to their pediatrician were brushed aside: they were "over anxious" parents who must learn not to worry.

When Derick was two, they insisted that he have an evaluation done at Children's Hospital.

> When we went to Children's I got the feeling that they thought maybe there was something wrong with me and not with him. They used the term "latent development"--he's just late. Again, they told us not to worry; he'd catch up. But I kept thinking how extremely late do you have to be for it to be right or wrong or for the child to need additional attention?

The actual report from this evaluation was sent to their pediatrician. When Marcia asked to see it, she was refused.

> The pediatrician said to me 'you wouldn't understand it; he's O.K.' I was furious. I said, 'Who are you to tell me what I will and won't understand?' I felt I was entitled to that information and was very upset that he wouldn't give it to me. But he insisted that it had nothing pertinent in it, and refused to let me see it.

A year later, they returned to Children's, and a CAT scan was recommended.

> Finally, a neurologist told us what was wrong. Derick had brain damage, and what he called a "fixed deficit." The doctor could't say what the full outcome would be; he said Derick would need some extensive, intensive help over a long period of time.
>
> Finally, the truth--after all that time. In a sense, there had been a two or three year waste, with me kind of fumbling along.

Marcia approached her pediatrician with her reaction.

> His response was that he wanted to "spare me." He felt it was better if parents realized these things gradually. I told him he took my prerogative away from me to pursue things further and do what I wanted to do.

After having spent the years trying to discern Derick's needs on her own, and after having exercised and stimulated him in every way she knew how, Marcia was "extremely exhausted." Although at three years Derick was barely walking, he was quite active and mischievous. Marcia was ready and eager for

one thing--to pursue some help. She had heard about Chapter 766, knew that it provided for three-year-olds, and was now ready to secure the long-awaited support they were all ready for.

Her first interactions with Paul, the Special Education Director of their town, were positive and responsive. Together they viewed a number of early intervention programs to determine their appropriateness for Derick. They decided on a twelve-month program in which parent involvement was an integral component.

The process was relatively new to each member who attended Derick's first IEP meeting. Together, the Clarke's, personnel from the early intervention program, and Paul cooperated in delineating appropriate goals and activities for Derick's first educational experience. This positive meeting encouraged the Clarkes, providing them with new information and allowing them to offer what they as parents had learned about Derick. Marcia and Raymond were confident that Derick's IFP was appropriate for him.

It wasn't until a year later, when Derick was to enter the public school system, that complications arose and Marcia found herself dealing with what she characterized as "deception, lies and bullshit!"

> As far as my comprehension of the process at the time was concerned, our second IEP meeting seemed to go well. But you see, I was missing some information. I didn't realize how detailed plans needed to be written in the IEP. For example, if the plan says, "Derick will have speech therapy," that's not enough. Later I learned that it has to say something more specific, like, "Derick will have speech therapy twenty

> minutes a day, five days a week!" I learned that as a result of the fact that Derick didn't get any speech therapy for most of the next year.

The day early in the year that Marcia innocently asked Derick's teacher how his speech therapy sessions were going was the day she discovered he wasn't receiving any at all. She directed her inquiries to Paul, who told her they were still searching for someone to fill the position. A speech therapist was finally hired in March, leaving Derick and his peers without individual therapy for six months. Yet, because individual sessions were not specified in his IEP, the school system replied that they were following the law by providing a speech therapist's consultation to Derick's classroom teacher.

Marcia was frustrated and angered by the information she had never received, and by her ignorance of the law's actual mandates. She began finding out some of the intricacies of the law, both from other parents and from a state advocacy organization, the Office for Children. And then she learned the development that was to devour any remaining trust she may have had in the school system.

> While Derick was receiving early intervention services, he was in a twelve-month program. At his second IEP meeting, no one informed me of the fact that they were changing his prototype, and I didn't know enough to ask. When I saw the twelve-month program become one which would last from September through June, I didn't think twice about it, because Paul promised us verbally that he would provide a program for Derick over the summer. I didn't realize until later that we would have no legal recourse if that promise wasn't kept.

Marcia started inquiring about summer programs in the late winter. She was well aware of the snail's pace at which bureaucracies move, and she wanted to guarantee that she would find a program for Derick.

> As far as Raymond and I were concerned, Derick unquestionably needed a twelve-month program. He had been doing well on a very, very slow gain basis, but he was moving and that's what was important. But it took a lot of very intensive work on the part of his school as well as on my part. Raymond and I felt it was critical that his progress continue. I'd even discussed the matter with Derick's neurologist who agreed with us. Derick learns and, thank God, he responds. And, with a lot of reinforcement, as long as you stick with it, he moves ahead nicely. But he tends to drop back the minute you stop doing things with him; he will forget and fall back into old habits. I didn't want any of the gains to be lost; it's that simple.
>
> And, to be perfectly honest, there was another reason for finding a good summer program. I had to find a summer program for Derick for my own mental health as well. Don't let the board of education hear this, because the parent isn't supposed to have any needs, but when I thought of spending every day all summer with Derick, with no respite, I was afraid--really afraid--that I would crack.

Marcia contacted a summer program the SPED Director recommended, only to discover they would accept children who were over seven, and who were toilet trained. Derick fell short of both criteria. She then tapped into parent and child advocacy resources that might provide her with another, more appropriate contact.

Her search ended when she found Lincoln Hill, a program that would offer a structured, behavioral education on a daily basis for seven weeks, with constant opportunity for

parent involvement.

Enthused by the program's appropriateness for Derick, she immediately called Paul to seek his approval. It wasn't until she later reviewed in her own mind his vague, pessimistic response that she realized he was indicating that funding would not be provided for Derick's summer program.

> I was really mad at this point. The politics of it all! That's my tax dollar, too. Don't they understand that it's better for them to take care of Derick now, so that he'll be able to become independent later? What's the use if he'll be having all these summer setbacks? He has potential. I think he has a good chance of making an independent life for himself someday, but only if everything is very intensive now, not later.
>
> I continued to pursue Lincoln Hill on my own as a possibility anyway, because it was so important that he get in, whether it would be funded under Chapter 766 or not.

Marcia kept contacting Paul, to determine exactly what was happening in terms of funding.

> I knew that I was getting a lot of mixed messages. And I began to feel that some of it was intentionally putting me off and that I was being told what I would simply call lies, just so that they could avoid dealing with me and what I wanted. I feel I am basically an open, honest person. To me, it's inconceivable that this deception was happening, but it was. I guess I'm a trusting person. I know now I never should have trusted that verbal commitment to a summer program; that was my biggest mistake.
>
> Paul absolutely refused to pay for Lincoln Hill. I finally got hold of the Chapter 766 regulations, which were very helpful. I

began to learn more of what was going on and what Derick was legally entitled to. I realized that all Paul had to do was write something up that said Derick in fact does need a summer program. It as as simple as his deciding there was a need there.

In fact, however, Paul stated he felt there was no need for Derick to be afforded such a service. Marcia's frustration became intensified when Derick's classroom teacher told her that she, too, was unsure whether Derick needed a summer program. Marcia vividly remembered the two of them agreeing to just the opposite a few months earlier. The teacher denied any recollection of that conversation.

At that point I felt there was a need to become extremely aggressive, because I got the feeling they know--undoubtedly they must understand--that I'm not in a position to fight and to look and to chase and to make all the calls and do this and that and the other. So that makes me more vulnerable. Therefore, they're going to take as much advantage of me as I allow.

When you put it all together--all the things that you're hearing from different people, and all the things that you're seeing for yourself, at some point you realize that if anything's going to happen, you're going to have to really fight for it and make it happen. You've got to be very, very sharp and aware, even if you're dealing with people you think you can trust.

Marcia and Raymond, thinking over the situation carefully, decided to take the school's decision to court. The money didn't bother them nearly as much as the principle in this instance. Derick would go to Lincoln Hill somehow, whether the school paid for it or not. But they were unwilling to

sit back and allow the school system to deny their child a service they believed he needed, if the year's educational efforts, both theirs and the school's, were to be maintained at all.

> The court hearing was scheduled within thirty days, for a Monday. The weekend before we went to a family camp, sponsored by our church. It was supposed to be a weekend of sharing with other members of the church community. However, there's a lot to be said for the comforts of home. Try living in a cabin with a five year old who's not toilet trained. Do you know what camp bathrooms are like? And at the time, he didn't have any eating skills. We had to carry him a lot because he couldn't get from one place to the other quickly, and he tires easily. We had to watch him at the water constantly. It was too much. We went on this weekend because we wanted him to have another unique experience, but when we got back, frankly, I was so wiped out, that I couldn't possibly have handled that hearing. I really couldn't have gone through the stress.

Marcia and Raymond made a quick decision to cancel the Monday morning hearing and managed to contact everyone involved to inform them in time. They planned to reschedule another hearing at a later date, but as time went on, the prospects of actually winning the case in court seemed to diminish.

Marcia and Raymond were impressed by what the highly structured Lincoln Hill program offered Derick, and they hoped that staff members would be helpful in defending their case at a hearing. By waiting until September, however, they found themselves in the middle of a state-wide controversy over whether summer educational programs not affiliated with a year-round school facility should be approved and funded by Chapter 766. As it appeared likely that Lincoln Hill and other such programs would lose their approval for funding,

the Clarkes were advised to drop their individual suit and see what the spring would bring.

Derick was one of a handful of children who returned to Lincoln Hill for a second summer. And, for the second summer, his parents paid the entire cost of the program.

CASE 5: DAVID

When Kate and Tim Murphy make eye contact from across the room and swap their telling grins, you know you've touched upon a personally important subject, one which has been a frequent topic of conversation between them. This subtle communication is easily initiated--merely mention the name of any one of their six children. Their supply of anecdotes about their children are appealing, affecting, never-ending. Their efforts to understand their children are ever-present; their children are important to them.

Kate looks young for her thirty-six years, with short stylishly frosted hair and a slim figure. Most striking is her calm, steady manner which comes through naturally in conversation. Tim is tall, stalky and good-natured. He, like Kate, exudes a friendly, easy-going manner, influencing the warm, welcoming atmosphere evident in their home.

David was the fourth born and is presently eight years old. Unlike the flirtatious, comic brothers closest his age, David's manner is reserved, observant, with a more subtle charm. Also unlike many of his siblings, David does not hold an "A-student" status in his classroom. His academic performance remains inconsistent, fluctuating from grades of 50% to 85%, within unpredictable cycles. He is

physically less coordinated than his brothers and sisters, and has trouble following along in board games they play at home.

Kate and Tim believe in a structured, disciplined approach to education. Each of the Murphy children who is old enough attends the neighborhood parochial school. Their parents appreciate the Sisters' firm commitment to teaching respect for God and neighbor and obedience to rules. Kate and Tim also believe the Sisters provide a high quality education. Although both parents periodically have some qualms with the methodology some Sisters incorporate in teaching, they do believe a child leaves a parochial school "knowing the basics," something that the chaotic public education system in their city is infamous for failing to accomplish.

Both parents actively inquire about their children's studies and review certain homework assignments on any given evening. When David's second grade teacher asked them to make a concerted effort to work with him at home on reading, they were happy to comply. Yet, they had little indication even then that reading was to become quite so problematic for David. It wasn't until he was in the third grade that they learned from David's teacher, Miss Stronge, that he was painfully struggling to read in school. Miss Stronge told them David was reading at a 2.3 grade level, and working in the "slow group" in the classroom. Neither of these facts was necessarily alarming, according to Kate, but they were intensified by Miss Stronge's deep concern from observ-

ing him while he read.

> When Miss Stronge would call on him to read in school, his fist would be clenched, and his face would kind of twist up. It was becoming a real physical struggle, and she was worried. She was having a terrible time teaching him, and couldn't understand why.
>
> The first thing I did was have his eyes tested, but the doctor said that everything was fine. Yet Miss Stronge had told us that with his IQ of 130, she believed that he should have no trouble at all. She figured he should be at least comfortably plugging along, even if he isn't putting his best foot forward. She was convinced, we both were, that he should not be having so much trouble.

Kate began to watch more carefully when she and David were reading together. One day soon after her conversation with Miss Stronge, David looked up from his book, one eye blood shot and obviously strained, and said, "When I look at the page, all the words are together and I have to pull them apart."

It wasn't long before Miss Stronge and Kate began discussing the need for a reading specialist's diagnosis and support. There was some intimidation about broaching this subject with Sister Michael, the principal of the school, given her well known philosophical opposition to individualized instruction, and her belief that David's inconsistent school performance was due to "laziness." Miss Stronge and Kate strongly disagreed with this stance, and felt the need to understand the root of David's

problems and intervene with more appropriate teaching methods. Thus they boldly requested an IEP evaluation be conducted for David.

Predictably, Sr. Michael was displeased with the idea of going across the street to the public school in the middle of the day to hold a meeting for one child, while twenty-four others sat in a classroom with a "babysitter." But she agreed to initiate the process and make all the necessary arrangements.

Once the assessments were completed, Kate requested that she and Tim be sent a copy of their findings prior to the IEP meeting. She was forced to make the request a few times before she received the evaluations, and in reading through them, she actually understood very little. Both she and Tim were anxious to hear the results explained and the recommendations made by the professionals on the IEP team.

They left the meeting in disappointment. Tim reports first:

> The whole atmosphere in that meeting was that everybody was in a big hurry. All these professionals came late, and as soon as they sat down, they all kept looking at their watches as if they had someplace else to go.

Kate adds:

> There were fifteen people there altogether. The principal of the public school stood at the door and threw questions at us from across the room challenging what we said.

> She would say, 'Tell me what you meant when you said that?'and I'd be sitting there saying to myself, 'Oh, God, I said that fifteen minutes ago. What did I mean?'
>
> We felt as though we were really on trial. We were left with the feeling that something was wrong and that we had made it wrong.

Within the meeting, the public school specialists stated that the results of the evaluations showed David to be a "classic dyslexic or learning disabled child." They were also quick to reassure his parents that the problem was mild. In fact, they suggested that the Murphy's not even worry about the problem for now. Kate reports:

> The professionals kept saying 'Wait and see what happens; it's not severe.'
>
> But my concern was that the problem was severe enough to interfere with his learning. It was interfering academically, and it was interfering socially. He was obviously not working up to his potential. My reason for having an evaluation meeting was to find out as soon as possible what could be done and to work with him right away. I didn't want him to be in the seventh grade, feeling like a failure and acting out. As a mother, I'd seen a problem, and I wanted to do something right away before it did seriously affect him. But all they kept saying was, 'Wait and see what happens.'

One programmatic option that was offered within the meeting was to send David across the street for an hour each day, to work with a public school learning disabilities specialist. The professionals at the meeting, however, felt

that such a program would do more harm than good for David. They stated that he was a child "affected by change," and that such a transition each day would in fact be "detrimental" to David. Because David's problems were not considered to be "severe" by the professional team, the recommendation was made to keep him in his regular classroom, with the hope that the Title I reading support he was receiving would be maintained throughout the next year.

Although Kate and Tim thought they agreed with the decision not to send him to the public school each day, they still felt unsure. The team was deciding, in effect, to do nothing to help David, and somehow that didn't seem right. In retrospect, Kate says,

> I'm afraid I still didn't understand much of what David's problem was, and I just didn't know the questions to ask.

At the meeting's end, they felt the need for some time to ponder its content. Although they were pressured to sign a blank IEP form before they left the meeting, they insisted on seeing the written results of the meeting before they would put their signatures anywhere.

> After the meeting, the more Tim and I thought about it, the more we felt the diagnosis was not specific enough. To say that he had a weakness in learning, I knew. They said back to me everything I had said to them.
>
> When I asked them what his best mode of learning is, they said it was impossible

to tell. They told me to watch him through school and go step by step and see how things go. But I don't buy that.

They may not be saying this, but what I'm beginning to sense is that because there are plenty of kids out there who have real serious problems, and David's isn't so serious, these professionals don't want to make the time for him; he's not severe enough. But it doesn't say anywhere in the law that you have to have a certain level of difficulty in order to be helped.

So I had to kind of get through that and stop feeling badly about all these other kids who were much worse. I decided that it's my responsibility to take care of this child who is in my care -- whether he is bad, or not so bad -- and keep things from getting worse.

When the IEP arrived in the mail, Kate remained dissatisfied with what she considered to be the vague, virtually useless information she had been given. She then sought advice from other parents who had children with learning disabilities. Having carefully considered a friend's suggestion, Kate decided to request an independent evaluation to be done at Massachusetts General Hospital, in order to obtain a second opinion.

She began immediately to make the string of phone calls, arrange the customarily delayed appointments and anxiously await the tests dates and finally the results. In the end, Massachusetts General was not much more informative than the school had been in their evaluation.

The doctor leading the Massachusetts General evaluation explained carefully to David and his parents and teachers that David had a mild learning disability. Specifics were difficult to uncover and, he considered, less important. He felt that any good teacher should be able to work with David to improve his reading, and that the services of a specialist were unnecessary. His major emphasis was that David himself would need to work harder and longer than other kids to make up for his deficits, and that he should receive as much individual support in school and at home as possible.

In the end, Kate and Tim are not much further along in understanding the mysterious label, "learning disability" than they were when they started. They remain confused, unsettled. When asked in retrospect for a reaction to these experiences over the last year, Tim responded first:

> After all we've been through, the bottom line is still 'wait and see.' You can go through all the tests, but still nobody can tell you anything really, absolutely definite.
>
> Even if we work and work and work with David, there are still no guarantees that things will work out all right. It's still 'wait and see.'
>
> I guess I didn't really expect any definite specific answers, maybe because everything they know about learning disabilities is so new. The professionals are kind of just feeling their way through.
>
> Perhaps in years to come, they'll know better how to diagnose these problems and help David. But to just tell him to work harder,

I think that's something that we would have done anyway.

I'm glad we did what we did. He's our kid and we'd like to explore everything that's possible. But I bet five years from now, they'll have definite more specific things to say about learning disabilities.

And Kate offered her perspective:

One thing that has come out of all this is a more relaxed David. Talking about these problems with him has helped him accept and deal with them better.

But, in the end, I'd say that although this whole experience wasn't actually devastating, it came close to being that, and it was certainly a waste of time. Had I known what we'd be going through, I would have gone and paid for my own evaluation right from the start without going through this city's system. I would avoid the law at all costs. It wasn't worth it -- all the phone calls, the endless hassles, not knowing if you're right or wrong. You're at the mercy of a lot of people who have a lot of paper work on their minds. They're good people, I'm not saying they're not, but I don't know if they can really do all that the law says they should.

CASE 6: SAM

Karen and Gregory are the adults who parent the Spencer family of five children, plus an occasional foster child. Karen is quick to laugh at the image of the "average family" portrayed on television: "Just once I'd like them to come to this house and see how we live." She is also amused by those who complain loudly that they simply cannot maintain a family of four on an income of $18 to $24 thousand per year:

> We've got five kids and we're living on half that--$10,000 a year. I'm sure there are people poorer than we are, and all I can say is, God help them!

Sam is the Spencer's fourth born. He was diagnosed at birth as having Down Syndrome. At six years, Sam is an attentive blond-haired, blue-eyed, pot-bellied, red-cheeked youngster who enjoys playing, eating and signing. His major developmental delay has been in the area of speech and language.

Although Karen and Gregory were initially confused about the implications of Sam's diagnosis, they didn't have to remain in the dark for long. They were immediately invited to become involved in a long-term Down Syndrome research project run by Dr. Purcell through Boston's Children's Hospital, which provided them with information, services for Sam, and support for themselves.

The project was an instant success as far as Karen was concerned--she was given ready answers for any query or confusion that arose during Sam's early years. What was particularly relevant for Karen was the support that developed

from Dr. Purcell and the mother's group he organized. The fact that this group is still meeting every other week speaks to the overall importance of the group to each of its members.

Yet, even with such a strong network of early support, Karen had a difficult time coping with the fact that Sam would be retarded.

> For two years, I gave Dr. Purcell and his group the answers I thought they wanted to hear. It wasn't until I was pregnant with Sally that I was finally ready to tell them, and me, what I was really feeling. I told them that I don't really think it's wonderful that God gave us a Down Syndrome kid. I'm mad as hell. I don't want one, and here I've got one. What am I going to do?
>
> That's when they provided a psychiatrist for me to see. I saw the psychiatrist regularly, until after Sally was born. But by then, I finally felt like I was on top of the situation. I said, 'I'm tired of feeling sorry for myself. Now it's time to do something about it! That's when I started taking control and delving into all the school stuff for Sam.

Although she had gathered the strength to pull herself together and to take control of her situation, she admits that depression is never quite far enough away. On occasion, burning a pot roast is enough to set off tensions and emotions that she realizes are always there, suppressed. It's a tenseness she never knew before she had Sam.

When Sam was three years old, Dr. Purcell's project advocated for Karen and her friends in her support group to seek early intervention services for their children. At the time, the Spencers were living in Whitney. Their introduction to the IEP process through this community was pleasant,

supportive and encouraging.

> That first IEP meeting was great! Gregory came with me, and we met all kinds of really nice people. They gave us coffee and donuts. They planned the meeting during school hours, so I didn't have to worry about a baby sitter. And, in the meeting, they asked us for suggestions on what Sam's program should include. We got a copy of his IEP in the mail to review, and a week later we got a final copy to sign.

The Whitney schools were open to having parents come visit their children's classrooms. In fact, they would send a taxi to bring Karen to observe Sam's program if she didn't have another way of getting to the school.

This supportive situation served to enhance the positive feeling Karen had in regard to the service delivery systems during Sam's early years. It also set up expectations for services and relationships with service providers that have since proved to be unrealistic. She puts the blame in part on the fact that as Sam becomes older, his needs become more intense and demanding. But she also points to their move to Placerville as the turning point that has, in fact, shattered her faith in the school system.

The situation which occurred when she first moved is a familiar one: she was intimidated at the first IEP meeting which focused on test scores presented through professional jargon. As a parent, she was not asked for any involvement other than a signature on an already completed IEP.

When it came time for Sam's second IEP to be developed in Placerville, Karen took the liberty of writing a note to

Sam's teacher, Sheila, mentioning the expectations she had for the upcoming meeting's process:

> I want this to be a planning meeting. I don't want there to be a piece of paper all ready for me to sign. I want to have some input. I want to be able to give you my ideas as well as to hear yours.

Karen arrived at the meeting to find only the teacher and the speech therapist in attendance. In this situation, Karen felt freer to express her opinions, although she remained fairly meek until they reached the issue of how much speech therapy Sam should receive. The school's maximum offer of two days per week was unsatisfactory to Karen, who understood only too well that a deficit in this area was Sam's most prominent problem. Although it took all the courage she had, Karen refused to sign Sam's IEP until they added more time with a speech therapist.

The decision to disagree with the school was a trying one for Karen. Although she certainly could not be considered a shy person, she, like many other parents, feels both a lack of confidence and assertiveness when facing a disagreement with the school system. She soon sought the support of a state advocacy agency, the Office for Children (OFC), to reassure her of her rights under the law.

With time, an extra speech therapy session was added to Sam's schedule, while a few added grey hairs appeared in Karen's curls. The wait for the decision, the phone calls, the months without an educational plan, the speech therapy time lost--all combined to make a concerned parent, worried and angry.

Yet, some of Karen's frustration was eased when she channeled her energies and became involved in a project whose focus was to train Placerville parents to use behavioral techniques in teaching their developmentally delayed children. A series of workshops was offered to parents, along with regularly scheduled home visits provided by staff members, to assist in the development and implementation of skill teaching and behavior management programs in the home.

Karen was a good student, and she and her "teacher," Angela, developed a close bond. In fact, Angela still maintains her visits to Karen on a regular basis as a teacher and a friend, although her involvement and responsibilities for the parent training project have since ended.

Karen feels good about what she has learned from this project. In fact, as her own teaching skills improved, she felt she was able to look more carefully and to critique more capably when she went into the school to observe Sam's program, which was at least a monthly event. It was when she became vocal in her criticisms, that she was banned not only from the classroom, but the school as well.

Karen returned to the Office for Children to determine if she had any legal recourse to the school's actions. To date, the OFC has been unable to find any rights which the school has violated by forbidding her entry into the classroom. Karen is left feeling uneasy because she is no longer allowed to observe even an hour in Sam's school day; she is skeptical about what is actually taking place in his class without any parent monitoring. In addition, she is becoming increasingly leary of the goals and behaviors his teacher has priortized within Sam's program.

> Since the parent training project, I can see more clearly what Sam's goals should be. Some of the goals his teacher has written in his ed plan just don't make sense to me any more; her priorities are different than mine. I mean, she wanted to spend time teaching Sam to zipper his coat and button his shirt. Well, that's a good idea, but it's something I think is more for me to teach him at home. I would rather see her spend the time teaching him four colors instead of three. I learned from the parent training project that I could teach him his self help skills here at home, and that I could even work on colors and counting and things like that. But when I went to the school with my own ideas of the goals they should be working on, all of a sudden everybody's back was up about the whole thing. Evidently, nobody had ever before argued about their kid's ed plan.

The only input Karen has as a parent to help to strucure Sam's educational program, is through the development of the IEP. Last spring, when Sam's teacher and Karen sat down together to develop Sam's IEP for the following fall, Karen felt the process was far from a cooperative, "team" effort. Although she disagreed with some of the goals Sheila prioritized, Karen didn't feel competent enough to "make an issue" out of their disagreements. Karen felt depressed after the meeting, and relayed some of her frustrations:

> Sheila feels like she has to do everything by the book, but sometimes, that's just not how kids learn things. For example, Sheila feels he's not ready yet to learn how to put on his shoes. So, she has never noticed that not only can Sam put his shoes on by himself, he can also tie them part way.
>
> Sheila's always telling me his test scores on the Stanford Binet, but I don't give a hoot about those test scores. I bet if you tested Sam two days in a row, you'd get two different scores, depending on how he was feeling. So all the tests and all the graphs don't make any difference to me.
>
> What Sam needs is something they just don't want

to let him have in Placerville--integration. Sheila thinks Sam's exposure to regular kids should be limited; she doesn't think he's ready for integration yet. But I think that Sheila is being too overprotective, even possessive. She's afraid to let him walk anywhere, even to the lunchroom, without holding her hand.

But I think it's important to let him go--to let him try! I took him to the Lincoln Park Fair last weekend, and I let him wander around. I was so proud of him! Except for his speech, you would have thought he was normal. He went up to talk to people, he waited in lines to go on the amusements, and he handed the men who started the rides his tickets. He really fit in.

It just makes so much sense that he should be with normal kids more often in school. But I just don't know how to tell Sheila these things.

CONCLUSIONS

PROCESS AND OUTCOME

The experiences described in the six case studies, and substantially corroborated in the additional interviews with 45 family representatives, testify to the complexity inherent in any attempt to understand "impact." Particularly with regard to P.L. 94-142 and the not infrequent emotional considerations that, for family members, attend its implementation, one is at a loss to explain the effects upon parents simply, or even without equivocation. For woven inextricably throughout any objective interpretation of the impact of P.L. 94-142 on families with disabled children are unyielding subjective issues related, for example, to parent self-confidence or their "coming to grips" with the fact of their child's disability. Such variables, while not formally addressed in the legislation, must be understood as no less vulnerable to being impacted upon than are the more procedural and programatic variables explicit in the law. Indeed, it remains our impression at the end of the first year that it is in the domain of the interpersonal, the subjective, the "parent-as-person," that the impact of P.L. 94-142 is most dramatic.

Viewed another way, the question of impact can be divided into considerations having to do with: 1) process; and, 2) outcome. Where a child ends up as a consequence of the procedures mandated by P.L. 94-142 (outcome) will often indicate little if anything about how he or she--together with the parents--got there (process). Is it more or less important, for example, that a child is finally placed in an appropriate educational program than that his parents

have been physically and emotionally drained by the responsibilities they found necessary to assume in order to ensure that placement? Is it more or less important that parents experience new respect for the sensitivity and skill of educators and clinicians than that the adequacy of their child's educational program remains unaddressed?

The obvious answer is that in each case both process and outcome ought to be equally considered if the final understanding of impact is to be complete. The obvious answer, however, avoids the question of representativeness and ultimately of the validity of that final understanding. Equal consideration of process variables and outcome variables when, from the parents' point of view, one category of variables clearly overwhelms the other serves only to yield a distorted final presentation.

This is a study more about parents and their response to the law than about anything else. Increasingly, as we listened to and learned about different parental experiences related to P.L. 94-142, we found ourselves unable to avoid a sympathetic bias in the direction of parent appreciation. These are tough, admirable, sometimes conflicted individuals to whom P.L. 94-142 offered an unprecedented promise (outcome) and for whom it proposed new responsibilities, new forms of involvement in the planning of their children's educational programs (process).

Unavoidably, maybe irresistibly, our interests swung consistently to process. While not unmindful of outcome -- indeed, from the objective educational perspective, the disabled children represented in our sample fared well for the most part -- the potential clues to greater understanding of the law's impact were too strongly and too often suggested by the more compelling variables related to process. And since these are relatively unaddressed in the research literature pertaining to P.L. 94-142, this emphasis would appear to be not only important and justifiable but also timely and necessary.

In what follows, we summarize the case study experiences according to five major provisions of the law in terms of the educational, personal and social consequences experienced for the child and family.[1] Both process and outcome variables are reviewed. For the reasons expressed, however, the greatest import is attached to understandings of the process experienced by parents as a result of P.L. 94-142.

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[1]Economic consequences upon families, while unattended to in Year 1 data, will be reported upon in our second year's efforts.

IMPACT OF THE LAW

In a recent publication of The National Academy of Gallaudet College (Yoken, 1979), nine profiles of individuals living with deaf-blindness are simply, clearly, and humanistically presented "to introduce students and professional workers to issues in the lives of deaf-blind individuals." The publication, based entirely on interviews, was undertaken by Gallaudet not for purposes of research but for purposes of service, not in order to discover findings but to develop familiarity. Nonetheless, in the final chapter of Nine Profiles, the author cannot avoid commenting on the kinds of learning that resulted from getting to know some individuals in depth.

> Drawing conclusions can be dangerous -- but not drawing conclusions can be more dangerous. Many issues appear repeatedly in these profiles, to the point that patterns of experience and response begin to emerge in the lives of the people interviewed. That recurrence alone warrants the issues' further examination.
>
> (p. 157)

So it is as well with the learnings from this pilot year. The parents we came to know demonstrated that indeed they have been affected in significant ways by the implementation of P.L. 94-142. They have, in addition, proven to be articulate, savvy and uniquely informative spokespersons for a number of issues directly related to the day-to-day workings of the legislation. In their roles as participants in the development of more appro-

priate educational programs for their children, they have acquired insights, developed tactics and raised questions that merit serious attention in ongoing efforts to monitor the progress of P.L. 94-142.

This section selectively reviews what we have learned to date from a small sample of parents, and suggests that careful listening, observing and reporting from the parent vantage point need to be continued.

Protection in Evaluation Procedures

The provision in P.L. 94-142 which protects a child from unfair evaluation procedures includes the following components:

- tests and evaluations must be free from racial or cultural bias;
- tests and evaluations must be comprehensive in their scope, with no single test providing the sole criterion for determining an educational placement;
- parents have the right to seek an independent evaluation if they are dissatisfied with the results of the school's evaluation.

When full compliance to this provision is upheld, the educational consequences for the special needs child will be significant. Comprehensive evaluations will provide a thorough understanding of the child's strengths and weaknesses and will allow for informed contributions to be made toward the development of an adequate and re-

sponsive educational program.

Of the six case study families, only two initiated any discussion of issues relative to the PEP provision. In the Murphy case, as detailed earlier, the parents were frustrated with the results of David's evaluation. The Murphys were satisfied that the evaluations took place and that the results were carefully explained to them. They were also made aware by another parent that the option for an independent evaluation existed. Their frustrations were twofold: 1) with the inability of two teams of evaluators to actually define David's learning disabilities; and 2) with the "endless hassles" imposed upon them by their city's school systems, which drained energy and emotion at a time when neither could be afforded. While they were more sympathetic with the evaluators, having come to understand the vagueness still inherent in "learning disabilities," they remain less understanding of their city's bureaucracy and doubtful of its capabilities.

The Kelleys also reported being frustrated by the experience of seeking an evaluation for Jake and they were to remain unaware of its results. The Kelleys came away from the evaluation process ignorant of both what was being assessed and of the results of the assessments. They were offended by what they perceived to be the evaluators' condescending attitudes. They have seen no evident benefits from the evaluations for Jake. We have not looked to the clinicians involved to determine their views of the same situation; perhaps they would offer

insight to this particular instance. Yet, Jeannie and Richie are not alone in the reporting of little or no understanding of test results; it is a common lament among parents.

At the time, Jeannie and Richie were unaware of their right to an independent evaluation. If they had been aware, it is doubtful they would have initiated the process: the first time through was reportedly too devastating.

In reviewing the case study reports and considering possible reasons for the relatively silent response this provision inspired, we think back to the 45 families interviewed informally during the pilot year, and are led to hypothesize the following: Parents are, more often than not, excluded from the evaluation process, and left with less than a total understanding of test results.

Evaluations are surrounded by an air of mystery. Numbers from test scores are provided, though generally not explained, when results are requested. Complex jargon is offered in place of clear description in discussions of the tests' content and to the person unfamiliar with tests, the professional rhetoric proves unsatisfactory if not meaningless. Few attempts are reportedly made by professionals to de-mystify assessments and to sensitively apprise a family of their results. There are, as the Murphy case illustrates, rare exceptions.

Keeping test results only within the province of the professional inhibits and sometimes excludes the parents from informed participation in the planning of their child's educational program. As Richard Weatherley observes in his well considered account of the implementation of the IEP process in Massachusetts:

> The exclusion of parents from participating in planning and decision-making need not be an inevitable consequence of the use of shared technical language by professionals..... Bureaucracies must find ways to communicate with clients; how well they do it depends on the importance of such communication for the organization. If the involvement of parents is seen simply as an additional bureaucratic hurdle, necessary only to satisfy procedural requirements, it is not likely that school personnel will take the trouble to make themselves understood to parents. However, when they want to, they can.[1]
>
> (p. 56)

We are left with no clearer impression from the first year of this study than that parents are capable of being productive and articulate colleagues on the educational planning team for their children. If their capability is to be realized to the fullest, then it would seem that the mandated parent-professional partnership must be valued by the professionals from the outset. In most cases, the outset begins with the PEP provision and with the opportunities for fruitful communication that it affords.

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[1]Weatherly, Richard A., Reforming Special Education: Policy Implementation from State Level to Street Level, the MIT Press, Cambridge, Massachusetts, 1979.

The Individual Education Plan

The Individual Education Plan is the document which details a child's short-term and annual educational goals and delineates the specialized services to be provided to meet these goals. The IEP must be developed with input from a team which includes, but is not restricted to: a special education representative from the school, the child's teacher and the child's parents. The IEP provision also requires periodic review and revision of the educational plan.

All of the case study children have IEP's signed by their parents. In all cases, at least one parent attended each IEP meeting. All six families, however, reported some problems with the process of developing the IEP's as practiced by their respective school systems. As detailed earlier, these problems vary; the key issues are reviewed briefly below.

Intimidation and poor parent-professional communication, as addressed above, are again found in parent reports of the IEP experience. In addition, we found instances where IEP meetings were conducted without all the required members being present. Bureaucratic complexity and a reluctance on the part of school systems to provide special services were also perceived by the parents in this study as not infrequent occurrences. Finally, parental experiences continue to reflect a basic inadequacy of information with regard to their rights as provided for by the law.

In the Kelley's case, for instance, although the IEP team leader recommended and planned for a seven-week diagnostic program which both parents approved for Jake, the placement was denied by the city's central office in less than two weeks. In its place, a new IEP was written by the team leader without reconvening the team. Jeannie and Richie reviewed it, changed a few goals, signed it and then sent it back for approval. A delay of six months was to take place unexplainably from the time the parents signed the IEP to the time it was approved by their city's bureaucracy. Only after this delay was Jake finally allowed to enter school.

In the Spencer's case, with each different IEP meeting Karen has attended, the process has varied. Her initial experience with the IEP process was positive, cooperative and supportive; she left feeling encouraged and respected. She moved away from this school system, however, and her first meeting in a new city was similar to many other meetings reported by the 45 families interviewed last year. Karen was quickly made to feel like an unwanted interloper at this IEP meeting, where singular attention was focused on test scores presented in technical jargon that for her held no meaning.

The next year, Karen attempted to avoid a similar situation by pointing out to Sam's teacher, in writing, that she was expecting her child's IEP to be developed in a "real" planning meeting. She also emphasized that she wanted to feel welcome to offer what she considered

to be her valid input. The meeting took place with only the teacher and the speech therapist, and even though it was marred by a disagreement with both, Karen was nonetheless relieved and encouraged by being allowed to express her opinions.

Marcia Clarke's first interactions with IEP meetings were reported to be as positive as Karen's initial meeting. She too felt the conditions were cooperative and supportive. Yet, she admits to not fully understanding the amount of detail required within the educational plan, and that verbal promises not included in the IEP were not necessarily services that would be provided.

> ...if the plan says, 'Derick will have speech therapy,' that's not enough. Later I learned that it has to say something more specific, like, 'Derick will have speech therapy 20 minutes a day, 5 days a week.' I learned that as a result of the fact that Derick didn't get any speech therapy for most of the next year.

Marcia had also signed this same educational plan knowing that it was the first of Derick's IEP's that did not provide for a summer educational program. She was initially unconcerned because during the meeting, the SPED director had told her that he would see to it that Derick would receive summer services. However, when the time came, payment for a summer program was denied; the promise was never realized. Marcia felt deceived.

Elaine and Mary are the most experienced mothers

in our sample; they are also the most assertive. They tell us they've learned to become assertive and knowledgeable about the laws because they've had to; if they were unaware of the provisions of the law, they report, chances are great that their children would receive less than what they need. As the case study descriptions illustrate, both Elaine and Mary can support their convictions with numerous examples.

The experiences of the case study families describe situations common to the sample of 45. We are led to hypothesize that while parents generally appreciate the potential benefits of the IEP provision, its pragmatic translation by the professionals responsible for implementing the law is less than satisfying to them. They express repeated concern that unless they are helped to become better informed and welcomed to become substantively involved in the decision-making process, the school will fall short of meeting the individual needs of their children.

The parents in this study want to be able to rely on the school as an advocate for the individual child in the IEP meeting, but as in the above cases, they've learned they cannot. They have instead found themselves having to grapple, often alone, with uncertainties about the educational plan, and with their growing sense of responsibility for their children's educational program. For many parents, this sense of responsibility reaches beyond their involvement in the development of the IEP. In fact, all of the case study families and more than

75% of their 45 family counterparts have found it necessary to monitor the school system themselves to be certain that the services prescribed in the IEP are in fact provided.

Karen, for example, visited Sam's classroom regularly until she felt compelled to critique his teacher's approach. She has since been banned from his school and remains concerned about the quality and appropriateness of the services he is receiving.

Mary O'Connell was forced into a monitor's role early in Robbie's educational career, years before the implementation of P.L. 94-142, as teachers and principals called on her repeatedly to complain about her son's behaviors. Mary sees advantages to this role. She realizes that she is the only stable participant in Robbie's educational career and as such considers herself a valuable resource to the different educators who continue to come into contact with him.

Parents within our larger sample also reported similar monitoring pressures: writing notes to teachers; making unscheduled visits to the classroom; using other teachers (and sometimes even their own and other children) as sources for inside information. Most of them felt they simply could not sign an IEP and rest assured that all would go as planned.

The Least Restrictive Environment

P.L. 94-142 requires that disabled children be

educated with non-disabled children to the greatest extent possible. Half of our six case study families found that segregated educational settings are at present the most appropriate for their children. One family is beginning to request more time for their child in the regular classroom; another child is mainstreamed for most of his day, while the learning disabled child remains in the regular class all day.

Karen has recently determined that her Down Syndrome son should be spending some time within the regular classroom to improve his social skills. His teacher disagrees. Although Karen feels strongly about this issue, she doesn't know how to convince Sam's teacher to try mainstreaming him for part of the day. Karen perceives this teacher as being somewhat overprotective of Sam, and she is hesitant to push for a partially integrated schedule when Sam's teacher is opposed. She continues to work with her son at home to increase his social and self-help skills, hoping that eventually she will be able to persuade his school that he's "ready" for mainstreaming.

Mary, on the other hand, has been initiating, pushing, demanding mainstreaming for Robbie for eight years. Mary is the first to admit that the mainstreamed setting has its problems. She worries about her retarded son's self-perception as he compares himself to his peers. She also sees the loneliness he experiences by not having any friends in Jr. High. Yet at the same time, she attributes what she observes as Robbie's steady positive social and personal growth over the years directly to the role models he's been exposed to in the mainstreamed setting. She

sees him learning to control his inappropriate behaviors in public situations; she observes his ability to engage in conversation and make decisions. Even his posture has improved.

Mary has weighed the effects of mainstreaming and decided that it provides the best learning situation for her son. We spoke with parents from 12 other families whose children were also in mainstreamed settings. Most agreed with Mary and advocated each year for increased time within the regular classroom for their disabled children. Others felt that the mainstreamed setting was becoming inappropriate for their children, and were now considering recommending more restrictive settings. We have found that families whose disabled children are mainstreamed have thought often and at length about the complex of substantive issues involved. It is from the interviews with Mary and with these twelve families that the following preliminary analyses are drawn; they form the basis for our more selective inquiries in Year II.

To examine the impact of mainstreaming upon these parents and their disabled children, it is first necessary to distinguish <u>what</u> they have to report with regard to the two critical groups who most influence the pragmatics of the mainstreaming experience. This includes a) the classroom teacher and b) the non-disabled classmates.

a. <u>The Classroom Teacher</u>

> I went in one day to observe my daughter being "mainstreamed" for science, and I saw her in the back of the room coloring while all the other kids were planting seeds. Do you mean to tell me that my daughter can't stick her

> finger in the dirt like any other kid and plant a seed? Later, when I asked that of the teacher, she said, "Oh, I never really thought of it that way." Now that's some thinking, wouldn't you say?
>
> Mrs. C

Almost to a one, these parents' confidence in the classroom teacher's competence is dramatically low. In the judgement of most, these teachers are demonstrably unequipped to perform their responsibilities satisfactorily in terms of the disabled child. Anecdotes about teacher performance in the mainstreamed classroom often sound like sick humor; "Can you believe that?" is a familiar attachment.

Yet, despite the parents' disillusionment with the classroom teacher's abilities, there are hardly any who critiqued with anger. They were careful not to fault the teacher, only to make observations about his or her performance. For, in the eyes of most parents, the teacher is no less a victim of circumstance than is the disabled child. And in the case of the mainstreamed classroom, the circumstance as perceived by parents is clear: inadequate administrative response to requests for inservice training. The teachers, say the parents, know they aren't ready. They know that the parents know that too.

> The teacher is more afraid of these new kids and how to teach them than I was ever aware of. If only she'd just level with me and say "I don't know anything about Down Syndrome." I could understand that. I could even maybe do something about it.
>
> Mrs. J.

b. The Non-Disabled Classmates

> Although the kids in Joey's classes are used to him, I don't know that they'll ever accept him. It's a real problem finding friends for him.
>
> Mrs. H.

To the parent of a disabled child in a mainstreamed classroom, the non-disabled classmates represent both a risk and a promise. These parents are more familiar than most adults with the unfamiliarity of typical children toward children like their own. They have witnessed the teasing, the name-calling and the rejection. As a result, they harbor substantiated concern for their child-as-target. They look to the teacher to protect, to make acceptance happen. Yet, as described directly above, they also worry about how well the teacher himself is prepared to accept disabled children; is the classroom professional in this instance any more understanding than the other students?

The extent of this concern over interpersonal relations varies among parents, seemingly in accordance with the child's disability. Parents of average intelligence physically disabled children, for example express quantitatively and qualitatively more worry about the effects of non-acceptance on their child's self-concept and esteem than do parents of retarded children. These parents express concern about potential harassment by non-disabled peers, sometimes worrying that the mainstreamed classroom may be inappropriate for their children.

Balancing this aspect of parent concern over peer interactions, however, is the value that virtually all parents perceive in having more appropriate role and behavior models available in the mainstreamed setting. After all, as parents frequently express, what are the effects on a child's self-esteem if the urge to protect leads to segregation in a classroom where many of the classmates exhibit strange or inappropriate behavior? What does it mean to a child to be identified as a member of "the special class?" And what does such a placement suggest about the kinds of behaviors likely to be modeled?

> When he goes into the resource room with kids who all have problems, he acts that way. He picks up their bad behaviors. Right now that's where all his classes are, and I'm worried stiff.
>
> Mrs. C.

> Last year Donald started in a resource room in the junior high. From the very beginning, he would come home crying, saying "What are you doing to me? Am I mental or something that you put me in that room? It's so noisy, Mom; I'll never learn anything in there."
>
> Mrs. D.

The issue of classroom interpersonal relationships is at the heart of what P.L. 94-142 means to parents; school, they understand, is a place where a good deal more than book-learning goes on. Yet it remains a particularly vexing issue for this report, an issue not readily susceptible to summary, an issue that demands closer and continued scrutiny. How, for example, does the age of the disabled child and his or her classmates affect the significance of the parents' concern? Is it

more of a worry for the parent whose disabled child is entering puberty rather than preschool? And in what ways might parent decisions about placement be influenced by concerns for the psychological well-being of the disabled child's sibling(s)? Are these children not also entitled to some parental worry as well? Finally, what is there to do about it all anyway? Boys will be boys, girls will be girls...it's a given. How much adaptation and accommodation can one expect in this domain?

Due Process

Parents have the right to due process hearing when they find a school system in non-compliance with a provision of P.L. 94-142, or if they face a disagreement with a placement decision for their child. In only one instance did a case study family look seriously into due process as an option for securing an educational service which the school had denied their son. In two other cases, the option could have been exercised but was not initiated.

Marcia and Raymond Clarke initiated hearing procedures as a result of their determination that the school provide the summer educational program promised to them by the special education director. As time passed, however, it became clear that if they were going to win, they'd have to wage a long and strong effort. The daily emotional drain of caring for Derick at this time wore so heavily on Marcia, that the thought of adding a situation that would only drain her further seemed hardly worth it. They eventually terminated the hearing procedures.

Elaine reports that in at least one instance she knew she had the right to a hearing, but preferred to use her own methods for persuading the system to comply to the law:

> They did not have a speech therapist, simply because they hired one and she left for another job. O.K., now I can go through this whole big court process, but to me it's stupid. By the time I would be finished with all the time it takes and all the money, they would have hired another speech therapist anyway. So, we just keep writing letters and complaining about it.

The fact that Jake sat at home for six months without a program while waiting for an IEP to be approved could certainly have been brought to the attention of a hearing officer. At the time, however, Jeannie and Richie were unaware of their right to due process. Yet, even if they had this information, it is likely they would not have exercised this option. They were new to the special education system; Jake's learning problems were still vague; they hadn't had much time to adjust to the fact that real problems did exist for Jake. At this point in time, it is a considered judgement that even had the parents been fully informed about due process, they would have chosen to avoid it. They were not yet prepared to deal frankly with the facts of Jake's condition.

Based upon our interviewing with the three families among the 45 who took advantage of the due process provision and our understanding of the case study families' experiences, it is reasonable to suggest the following set of pre-conditions as those which are likely to

facilitate parents' exercise of this provision:

(1) There are two parents concerned about the particular issue in question;

(2) They have strong convictions about what is educationally appropriate for their child, and believe that what the school is offering is inadequate;

(3) They are generally well-educated and have an adequate understanding of their rights under P.L. 94-142;

(4) They are emotionally capable of coping with a lengthy battle with the school system.

Parental Involvement

For the first time in history, parental involvement in making educational decisions for disabled children is both recommended and protected by federal legislation. It is clear from our presentation that parents have had much to say in relaying their experiences of this involvement.

There is no stronger theme throughout this report than that of parents as capable contributors to the planning of their disabled children's educational programs. As previously detailed, we have found parents rarely valued as partners in planning their children's programs. As participants in the IEP process, they find themselves uninformed: they feel lost within discussions of test scores; they are too often unaware of their rights. If parents are to become active participants in planning their children's educational programs, they must be apprised of their rights. School systems must establish

as a priority the dissemination of adequate, appropriate, useful information to parents at the earliest moments of the evaluation process.

DISCUSSION

In January 1979, the U.S. Office of Education submitted its first annual report to Congress on the implementation of Public Law 94-142. The report, "Progress Toward a Free Appropriate Education," is distinguished by clear presentation and by impressive empirical support from research investigations and related data gathering activities conducted nationally. Its findings are numerous, its information value substantial. P.L. 94-142, it suggests, while not without some problems, is on its way to working.

Nothing in the first year of our investigation competes with the findings of the USOE report in general. However, given the case study nature of our research, it has been possible to examine in some detail aspects of the implementation of P.L. 94-142 which received surprisingly little attention in USOE's report, and which appear to be of critical importance in continued efforts to monitor the progress of activities surrounding the law's implementation.

1. Parent Contributions

In the first annual report to Congress (USOE, 1979), a 1979 study of the attitudes and motivations of parents, teachers, administrators and other P.L. 94-142 participants was cited as support for the following conclusion:

> Many of those interviewed felt that individualized education programs would be beneficial since they would help keep parents informed, encourage planning on the basis of individual needs rather than the application of a label, and facilitate management and instruction.

> Many also expressed concern, however, that parents would not become genuinely involved--primarily because of their feeling that they could not contribute. (emphasis ours)
>
> Progress Toward a Free Appropriate Education, p. 93

On the basis of our investigation, the above conclusion is troubling on two counts:

a. Information

While it is true that participation in IEP planning proves informative to parents, it is nonetheless clear that this way of keeping informed is considered by parents to be neither reliable nor reinforcing. Indeed, it appears that what parents learn most about in this process is how uninformed they are relative to the other participants -- not with regard to their child, nor necessarily with regard to the intent of the legislation, but with "how the system works." As described earlier, parents more often than not leave this experience confused or intimidated, not really informed at all about anything other than the need to be more strategically prepared in the future. For that preparation, for that information parents turn first to other parents.

b. Potential

There was very little suggestion in our study that parents would hesitate to become involved in the educational planning for their child because of a feeling that "they could not contribute." Rather, it was clear that these parents: a) had significant, often unique, contributions

to offer about the educational needs of their children; b) were eager to enter their information into the planning process; and, c) were not infrequently prevented from doing so by others who presumed "to know better." Too often parents recounted instance of their information being devalued by other members of the IEP team either because predetermined placement decisions made their contributions irrelevant or because, simply, their semantics differed from the majority.

There is no clearer finding from this investigation than that parents have significant potential to be primary contributors to the IEP planning for their children.

It would seem that one of the most important responsibilities of the professional participants in the IEP development process is to tap the parents' potential for contributing meaningfully, to work with them to elicit the information only they have in a form that would be helpful and appropriate to the planning of objectives. However, the fact that parents continuously recall the IEP forum, with little satisfaction, as a first lesson in strategizing and as a reaffirmation of their distrust of professionals, strongly suggests that conditions for effective and appropriate parental contributions are far from well established.

2. Parent Involvement

We have examined in some detail how the case study families assume self-imposed, though not always welcome, obligations to become actively involved in their children's education under P.L. 94-142. While we cannot claim

that these patterns of involvement are a direct consequence of the legislation, there is much about this intriguing domain of behaviors that is sufficiently associated with the legislation that it deserves serious consideration.

It seems generally to be the case that parents initially perceive P.L. 94-142 as an invitation to become directly involved with educational planning for their children. This invitation, while it frightens a few, appeals to most. They look forward to offering structured contributions on behalf of their children. As we described earlier, however, this initial appeal quickly evaporates when parents discover that what began as an invitation very soon comes to be experienced as an obligation. There is a sense among them that they cannot afford to fade out their involvement after the IEP planning phase, that much as they would like to rest secure in their child's placement, they have now learned too much from their initial involvement to harbor any fantasies in that direction. A cycle of involvement begins. Parents feel compelled to monitor, to safeguard. Is the plan being followed? Are the classmates taunting? Is the bus driver smoking? What's the classroom temperature? Is my child happy there? Can I help that other parent with her problem? Should I appeal this placement? What about the summer program?

And above all else, who will care about these things, who will act on these things if I do not?

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